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LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY

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USE OF LIFE-SUSTAINING TECHNOLOGIES IN OTHER COUNTRIES

July, 1987

Legal Issues: Italy, by Emily C. Moore, Rome, Italy.

Elderly in Japan, by Rihito Kimura, Kennedy Institute of Ethics, Georgetown University, Washington, DC.

Legal Issues: Canada, by Holly Dugan, Johns Hopkins University Center on Aging, Baltimore, MD.

Legal Issues: Yugoslavia, by Christoph Haug, Johns Hopkins University Center on Aging, Baltimore, MD.

Legal Issues: Federal Republic of Germany, by Christoph Haug, Johns Hopkins University Center on Aging, Baltimore, MD.

The Medical Care and Treatment of the Critically Ill Elderly in China: Issues and Lessons for American Policies, by John Langenbrunner, Washington, DC.

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LIFE SUSTAINING TECHNOLOGIES AND THE ELDERLY

Legal Issues: Italy

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for the Office of Technology Assessment, U.S. Congress, 1986

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PREFACE

With sadness, I note here the unexpected death of my colleague's 30-year-old friend who had been receiving dialysis treatments. Mr. Geiser's work on this OTA project brought him into contact with medical personnel who pointed out that his friend would be better off having a kidney transplant -- especially since he was so young and would automatically have "priority." He intended to pass along this advice to his friend, who apparently had not been so advised yet and apparently intended to continue dialysis indefinitely. The friend's condition unexpectedly worsened. When a nurse was preparing to take blood from his arm, a nursing colleague pointed out that the patient was already dead.

His family believe that both the original handling of the kidney ailment (resulting in the need for dialysis) and their son's death resulted from medical misjudgment and mismanagement. They did not, however, permit an autopsy nor do they intend any legal action whatsoever. Case closed.

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I. INTRODUCTION

No one seems to believe that technology has much to do with the problems of the elderly in Italy: "It's not a question of technology, they need social assistance" (Crocella); "It's not technology, it's a sociological problem" (Mori); "It's not technology, it's a moral problem" (Merli).

Only indirectly is the problem viewed as "technological" or stemming from technological advances. Mori (ethicist and expert in jurisprudence) notes that before advances in technological health care made the prolonging of "vegetative" life possible, there was no need to distinguish between active and passive euthanasia. And demographers point out that the "technology" of contraception and safe abortion, together with changing economic and social values, have caused the sharp post-war decline in Italian fertility, which in turn has resulted in a serious aging of the population.

A. Demographic Profile: Aging of the Population

The population of Italy was 47.5 million in the 1951 census, rising to 56,244,000 by 1981 -- an annual increase of .064% in the 1951-61 decade, but only .038% in the decade 1971-1981. Post-war crude birth rates dropped from 22/1000 population to 11.3 in 1980 (well below the US rates of about 15). Crude death rates were 30 in the immediate post-war period, dropping sharply to 10 and remaining stable. Migrations abroad also declined, from over a million in the years 1951-61 to less than a quarter million in the subsequent decade.

In 1951 the population 60 and above number 5.7 million, or 12.2% of the total population, rising to nearly 10 million at present, or 17.4%. Persons over 80 more than doubled in 30 years, now numbering 1.3 million. Life expectancy was 65.6 in 1950-53, rising to 72.8 in 1974-77 (undoubtedly even higher now in 1986), due primarily to reduced natality and declining infant mortality.

It is projected that by the year 2000 (with continued low fertility and a net migration of zero) the population will number 56.2 million among whom the elderly over 60 will constitute 22.1%; nearly one fouth of the female population will be 60 and over. (Comitato Nazionale Italiano sui Problemi della Terza Eta, mimeo from the House of Deputies)

It is unnecessary to point out the specific changes in social and eocnomic life that these changes imply, nor the added burden on the health care system and social services (Natale 1981).

Italian Regions

1 - Piemonte
2 - Valle d'Aosta
3 - Lombardia
4 - Trentino Alto Adige
5 - Veneto
6 - Friuli Venezia Giulia
7 - Liguria
8 - Emilia Romagna
9 - Toscana
10 - Umbria
11 - Marche
12 - Lazio
13 - Abruzzo
14 - Molise
15 - Campania
16 - Puglia
17 - Basilicata
18 - Calabria
19 - Sicilia
20 - Sardegna

While it is risky to generalize about an entire nation -- whether the subject be national character, health statistics, or provision of public services -- it is particularly important in the case of Italy to point out regional distinctions. The North -- including French-minority zones in Aosta and German-speaking minorities in the South Tirol (Alto Adige) -- is generally more "European" in orientation and social indicators, while the South (including Sicily, Sardegna, and Calabria, as well as Napoli -- areas from which a large proportion of Italo-Americans emigrated) is more "Mediterranean" in culture, social and demographic characteristics. Rome is geographically central, but grouped for statistical purposes with the North (this despite large migrations post-war from impoverished southern areas which have strongly influenced life in the capital city). Some examples of regional differences: life expectancy at birth is 70.6/77.2 (male/female) in all-Italy (1977-79), but only 69.7/75.5 in Campania (Naples and surrounding province). Hospital beds per 1000 inhabitants are 8.2 in North-Central regions, only 6.2 in the South. Significant for the topics discussed here are proportions voting for the Christian Democratic party in the 6/83 parliamentary election: 37.3% in the South, 30.8% in North-Central. Divorces are more than double in North-Central areas (27.6 vs. 13.6 per 100,000 population) than in the South. Northern suicide rates are higher, while Southern crime rates are higher. Expenditures for social security and health are far higher in the North. (Istituto Centrale di Statistica 1985 and Istituto di Ricerche sulla Populazione 1985)

B. Role of the Family

From films, books, friends, and sociological literature, Americans have no doubt heard often how important in daily life is the Italian family. In Italy, one quickly learns that to have one's car repaired, a sofa re-upholstered, or to find a job, family connections are essential. The Family has also been likened to a small state: since the government does not provide certain services, the family must. Sickness is a prime example of the centrality of family care, where a good deal of nursing, particularly for the terminally ill, is expected to be done by female members of the family.

C. Role of the Elderly

The trend in Italy is not unlike that in many other industrialized nations, except that it is happening later. From a role as respected, wise, and in some ways powerful, the elderly person increasingly finds him/herself in the

role of the "peso" (weight, burden), particularly when sick. Most refuse to go to the few nursing homes that exist; despite names suggesting luxury (Villa Bella, etc.), such homes are very expensive and often accused of providing atrocious care. In limited instances a state-paid nurse provides domiciliary care, but daily chores for the frail but not sick elderly are expected to be performed by the family. The role of the elderly female is the subject of social research and journalistic attention, especially as many who grew up in a world in which divorce was unthinkable and women did not have paid employment now find themselves divorced, unskilled in the marketplace, and impoverished.

D. Attitudes toward Death

Death and funerals are often noted as a particularly revealing aspect of a culture, though often misunderstood by outside observers. Elaborate floral arrangements, mournful public processions for funeral cortea (snarling traffic for many blocks around), and minutely prescribed death-related ceremonies and duties are characteristically "Mediterranean" and thus more common in Southern Italy. (Americans who have seen too many movies might jump to the conclusion that expensive elaborate highly public funerals are invariably for decedents of the Mafia.)

Mori (see list of informants) characterizes Italian attitudes toward death as more "tabu", "closed," and "secret" than those of more northern countries. Others refer to Italian funerals as "highly emotional, sentimental," or as "occasions for family reunions." Italians visiting cemeteries in northern countries, for example, say they are struck by their beauty and openness (lacking high walls, family compartments, shields of cypress trees): "I've even seen people go to cemeteries to stroll /as in Pere Lachaise, Paris/; we're far too morbid to do that" (Mori). Caskets are open before the funeral, except of course in cases of gross disfigurement; widows are expected to kiss the dead husband. Cremation, opposed by the Catholic Church, is very rare.

E. Role of the Church

Nominally more than 90% of the population is Roman Catholic. To understand Italy at all, one must appreciate its close ties with the history and current center of power of a worldwide religion, and the recency of the country's political independence from the Vatican. (The first Concordat between Italy and the Vatican was signed in 1929 by Mussolini, only revised in 1984.)

This is not the place to draw conclusions concerning the de facto power of the Catholic Church over state affairs, as it is clearly still a matter of considerable public dispute. In fact, over the strenuous objections of the Vatican, liberalized divorce and abortion laws were passed in recent years. But the relationship between the Vatican and Italian politics can be viewed by quick reference to the role of the Christian Democratic party (DC). Italy's 45th post-war government has just been formed, with a 5-party coalition. The Prime Minister is a Socialist, but the largest party is Christian Democrat, about a third of the electorate. Together with three other right-of-Communist parties (but excluding the fascists) they make up the government. The Communist Party is the second largest vote-getter (actually the largest in the European Parliament elections last year); it constitutes the opposition. Until recently, the government of Rome was Communist, but has returned to DC control. The Church's role in all of this is ostensibly indirect, but generally acknowledged to be considerable. Pope John Paul II openly urges voters to vote for the DC party, and for decades it has been common practice for the full weight of the Church to have been brought to bear to assure the defeat of the Communist Party in various elections and referenda -- though the influence has not always succeeded.

In medical matters, as we will see below, the Church has considerable influence: many hospitals are Church-run, staff in public hospitals are often religious personnel; coinciding with the entry of the Communist party into the government of the city of Rome, the Vatican withdrew religious personnel from public city hospitals, creating a staffing crisis; large numbers of health personnel are trained in Church institutions, after having received Church-sponsored education; medical societies are a primary channel for dissemination of Church doctrine and current papal teaching. Papal decrees, speeches, etc., whether to medical societies or to Parliamentary deputies, are not "orders" but they are suggestions taken quite seriously by practicing Catholics and their colleagues, all of whom function in an environment heavily influenced by the Church.

II. STRUCTURE OF THE HEALTH CARE SYSTEM

(See also Appendix A, National Health Service.)

Italy has a comprehensive health law which applies nationally, to which regions may add their own laws and services; for example, in the regions "rosse e riche" (red and rich), primarily in the North, additional services are provided, such as social assistance, domiciliary care including social workers as well as nurses, etc.

Law #833 of 1978 was an effort to "rationalize" a fragmented system of separate provisions; various entitites existed according to the type of employee -- engineers, agriculturalists, lawyers all had separate health units. There could be an abundance of services in one quarter of a city while others were lacking. All entities were public, and it was obligatory to belong and pay in, both for health care and pensions. (Only the "liberal professions" and storekeepers were exempt.) The system cost more than it was taking in. Virtually all parties agreed to a change, including the extreme right which "didn't dare oppose" (Crocella). The Communists contributed to the formulation of the law, but by the time it was to be implemented, they were no longer part of the ruling coalition. Implementation has been slow.

All citizens, plus foreigners from countries with reciprocal agreements, are entitled to free medical care under law 833. (Its financing and operation are said to be similar to the British system.) Care includes physician visits, medicines, ambulances, hospital treatment, laboratory analyses etc. Gradually, certain categories of services have been excluded and certain fees introduced -- e.g., patients pay a small sum for prescriptions; dental care is excluded, as are thermal bath cures, certain specialists, particularly expensive technologies such as CAT scans (unless prescribed by a national health service physician and performed in a public hospital or clinic). Patients may choose their own doctor, many of whom provide services in both public and private settings. Those who wish to avoid long waiting lists (e.g., 60-90 days to enter a public hospital) and the grossest inefficiency may pay for private clinics and doctors. Private hospitals and clinics are less frequent in Northern regions because public services there function more efficiently. Services are provided in hospitals, clinics, and in ambulatori (or outpatient) settings, all of the above both private and public, with religious personnel in all settings. It is common to hospitalize patients for many days for diagnostic tests, especially prior to surgery. "Parking of the elderly /in hospitals/, especially in vacation time" is common (Manni 1985).

Hospices are virtually unheard of; the Italian word "ospice" is a "home for the aged." Italians generally prefer to die at home. "Why create a new type of health facility just to provide a non-hospital setting for the dying, which is what the family is supposed to do?" (Anon.) *

Families attempt to anticipate the time of death in order to remove the patient from a public hospital. If he dies in such a hospital, there are expenses in removing the body, but more importantly, the head physician legally has the

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Mori points out that UK/USA-type hospices can mute the issue of euthanasia, since comfort, pain alleviation predominate over life-sustaining techniques. (1985b)

right to order an autopsy. Legally, the family has no right to refuse, but if they "weep or threaten," the result may in fact be no autopsy. Autopsies are quite contrary to Italian culture, but the law permitting them passed under pressure from medical researchers "because there's never enough material for medical research" (Merli).

The 1986 finance bill, hotly debated in Parliament at the end of 1985, contains sharp cutbacks in all sectors, but health is to be most drastically affected. Only parts of the bill were actually passed, but other proposals have gone into effect by decree, such as a rise from £1000 to £2000 for each prescription, and a rise from 15% to 25% in the proportion of the cost of medicines and lab analyses that patients will have to pay; those in the poverty class would be exempt. (See Appendix B, "Goodbye Health Services.") The proposal would also regulate the number of beds, now 6.5 per 1000 population, to be 1 per 1000 within 3 years, and bed use to be not less than 75% (referring to non-acute conditions needing low-intensity care); hospital stays should average no more than 10 days for acute conditions.

The current National Health Service functions through a network of "local sanitary units" (USL). There are now 20 in Rome, for example, with proposals to create maxi-USL's or Super-USL's. (Letters to the editor point out that such a rearrangement of boundaries may ensure a hospital in every USL, but will not bring hospitals closer to homes. The present districts are based on political considerations, bearing no relation to the distribution of services, some of which are concentrated in a few zones of the city.)

Among the numerous recent "scandals" reported in the press concerning the health care system is the unanimous decision by members of Parliament to ensure that they will not have to stand on lines and trek from physician to authorizing centers; instead, a USL just for their own (and that of the constitutional judges and President) has been created within their work office buildings. "The men of the Palace /Palazzo Chigi, where Parliament meets/ have carved out for themselves an island of happiness in the chaos of the health bureaucracy. Not exacly a USL just for them, but almost so.... A 'little law' -- pased with unanimous accord of all political parties, from fascists to communists..." continues the article in Giornale (politically right-wing), noting that in such a way the elected representatives can shield themselves from full comprehension of the malfunctioning of the system for the ordinary citizen. (Giornale 1985).

The "scandalous" conditions (a term used regularly in the press in reference to health care) are graphically summed up by the plight of the USL director in Rome. The following poignant comments indicate his frustration at being charged with managing -- and presumably improving -- services, while being blocked in his efforts to do so by a variety of individuals, organizations, and traditional practices. Rome's situation is atypical in the sense that it is the capital and thus suffers many of that city's unique problems, but it can also be viewed as "representative" in the sense that conditions are neither so bad as in the South, nor as good as in the North.

In Lazio (the region surrounding Rome) there are more licenced clinics than elsewhere because the public hospitals barely function.

54% of the Lazio health budget went on these private services, in contrast to only 4% in Veneto (including Venice) and 12% in Lombardia (including Milan).

Health care absorbs a low percent of costs; most goes for administration. One hospital bed day costs £750,000 in licenced (private) clinics (about $400). "Private hospitals get rich on public funds."

USL number 1, in the center of Rome, where parliamentarians go, was contolled by the Communists when in power; USL number 2 by the Christian Democrats. Both are considered "showcases." USL 1 has a budget of £220 billion -- as a major industry -- with 2 specialist hospitals, 19 policlinics (outpatient), 3 private licenced clinics, 2 private religious hospitals, plus the Vatican-run Bambino Gesu (pediatric) and Bene Fratelli (on the island in the Tevere). It serves 150,000 persons with 1.3 million services annually. It has 2300 employees, including doctors. Half the budget goes to licenced clinics. £76 billion goes to staff, and £20 billion to current expenditures. There is nothing left over to build more modern structures or machinery -- and this is a "showcase" USL.

There are many reports to the police -- too many people in line, mice in cellars, cockroaches in the operating room, poor security.

"The fire vigil, unions etc. take me to court twice a week."
"Everyone is denouncing everyone else -- the doctors against the administrators, the nurses against the doctors, the unionists against the health directors. Now they're denouncing me, or threatening to do so, if I try to save money....Take the example of absenteeism. We uncovered a clinic where they signed out at 2 PM, then were registered only 5 minutes later at another medical center across the city. So I decided to install time clocks, but they reported me for anti-union behavior." So he decided to fight only the most important cheaters, the head physicians, who do as they pleased, but he was denounced to the court, and the court of last resort went against him, saying the

physicians have the right to organize their service hours according to their own needs. He then discovered that unique among 20 Rome USLs, there is the capacity to electronically control all pharmaceuticals, day by day, physician by physician. He tried to use this capacity to counteract over-prescribing; he found 12 physicians who repeatedly prescribed unnecessarily -- e.g., 20 prescriptions a day for one patient for months. From then on, there have been 300,000 fewer prescriptions a year, saving £4 billion a year in one USL alone. But when he tried to save £800 million on laundry that was being contracted out, he was denounced. He has been denounced because risk indemnity for radiology is too generous, denounced by a physician for abuse of power, by unionists for damanges caused to health by the hospital environment, by patients because their refunds were not provided promptly, and by companies because of lateness in revision of contracts (such as laundry service). He has been denounced by the pretura for violation of hygienic and accident security standards, and denounced for scarce use of the outpatient clinic. In fact, he says, it was he who pointed out that there were not enough physicians in the outpatient clinics and far too many pediatricians, which he has to keep on contract because of a union agreement; physicians who see no more than two patients a week are on full salary. Expenditures for bandages were reduced from £200 to £26 million after he prohibited their use as cleaning cloths (although it is suggested that the bandages might have been sold as well as having been used for polishing). But all such efforts to save are useless because expenses are based solely on historical experience, with automatic hikes in each category for inflation. Instead of putting money into new machinery to save billions, the system continues to function in the same way, benefitting only the firms which get contract work and the usual political parties. (Espresso, 1985).

At the time of writing, physicians all over Italy were engaged in a three-day strike, threatening others in the months ahead; hospitals have been reduced to emergency service, and the involvement of veterinarians threatens to halt commerce in animal-based products as well. There are a number of issues but the primary demand on the government is for a contract for physicians that is separate from that for other health workers, in order to provide doctors with "more autonomy."

To balance somewhat the plaintive lament of the USL administrator, we might add to the chorus of criticisms of the health service the points made in a recent hour-long TV program on the "politization of the health service" (by the Radiotelevisione Italiana 2). Some central comments follow:

> An elderly man was recently found dead -- after 8 days -- in the toilet of a USL office; the toilet obviously had not been cleaned for over a week.
>
> In one hospital, patients must whistle for care -- once for a doctor, twice for a nurse. A doctor sewing up a patient may find there is insufficient suture to complete the operation and have to "borrow" from another hospital nearby.

> It is now commonplace for patients to have to be moved from one hospital to another when "abandoned" by hospital staff who all go on vacation simultaneously.
>
> It is also commonplace to find elderly patients confined in hospital for months for no particular treatment.
>
> Our major problem is too ambitious a plan, attempting to provide everything to everyone, resulting in the "Spaghetti Welfare State" where no one gets served adequately; it's an effort to imitate Northern countries, but without their resources. Equality for all at any cost, ends up impoverishing all. We spend so much to enable everyone to have free care for their common cold that we haven't the funds for life-saving medicine.
>
> (The director of a private clinic contrasts the public hospital with his clinic. He served in the war resistance, was personal physician to a number of notable figures on the left, and his comments should be seen in that context.) If an elevator stops in our clinic, it's fixed in 10 minutes, or if the CAT scanner is broken, in an hour, while employees in the public hospitals leave when their hours are over, regardless of whether there's work to be done. Our personnel stay on the job. A patient can get a urinalysis done in our clinic in a day, thus costing only £700,000; in a public hospital a full workup takes 7 days and costs £2,800,000.
>
> The difference between the public USLs and private health services is because of the extremely poor management of the former, with layers of top administrators totally lacking in management experience; expenses in the public health sector are guesswork, year after year, with no one ever having attempted to predict them or suggest a ceiling; when they exceed expectations, as they always do, the public pays the following year in a variety of taxes.
>
> The bottom line is the importance of distinguishing the government's role as administrator from its political role. With only 30% of the vote, the Christian Democratic party holds 55% of the top administrative posts in the health service, many of them lacking management experience. We must end the notion of "party hospitals."

The above lengthy citations are included here in order to place the problems of the elderly in the context of a health service in genuine crisis. Decisions about access to care, selections of patients to receive treatment, and customs that have developed regarding the sensitive issues of terminating interventions are all found within the above-described situation. In the mid-1960s, there were barely 500 medical students at the University of Rome at the laurea level; now there are 22,000; many charge that the quality of their education has much deteriorated; and that the flow of wealthy patients to other countries seeking more adequate services is an expected result, while others maintain that despite all its difficulties, the system still manages to produce qualified physicians and other health personnel, has equalized access to services so that the poor now have far greater access to care than before the 1975 "reform," and that better management and "reform of the reform," including its depoliticization, will right the many wrongs that now form the substance of journalistic alarm.

III. THE RIGHT TO TREATMENT AND THE RIGHT TO REFUSE TREATMENT

A. The Right to Treatment

Apart from the conditions of law 833 noted above, we include the following: every patient for whom a doctor prescribes dialysis has the right, by law, to receive such treatment, although in practice it is a matter of "first come first served." The elderly patient is unlikely to be served even if he is first to come, however. ("The elderly often have grave complications on dialysis." Anon.) In fact, a third of needy patients in the public system do not have access, although some private organizations step in and provide machines, often located at great distances from patients' homes. Some are provided for in-home use.

There is no right to transplants. Indeed, large numbers in need go abroad, and there is a negligible number performed in Italy. (The Center of Organ Transplants assists some patients in need. Private collections for special cases to go abroad are reported in the press.) There is a widespread reluctance to donate organs; the Italian Association of Organ Donors is attempting to sensitize the public to the great need. Until eight years ago, the law required family consent to remove an organ for transplant; now the law requires only that the family not object. A proposed law would require everyone to carry a donor card — either a negative indication on the card or the lack of such a card would automatically indicate permission to remove organs.

"A generally healthy 80-year-old has the right to any and all treatment that persons of younger ages have. The de facto treatment that varies by age becomes an issue only when the elderly are seriously ill." (Merli) The elderly receive antibiotics in a manner no different from younger patients; abuse of drugs is "common all over the Western world." (Anon.) With few exceptions, if you can name it, you can buy it in Italian pharmacies, without prescription; many say that doctors overprescribe because they feel that patients do not feel adequately treated unless they leave the office with at least three prescriptions.

There is no such thing as formal "do not resuscitate" orders; hospital personnel ALWAYS try to reanimate patients, reagrdless of age." (Merli) When the elderly person, or the not-so-elderly person is in coma and is

a famous personality, such as the 61-year-old writer Calvino (see Appendix C), no doctor dares NOT to continue with all possible means, even after publicly announcing that the individual is brain dead. (Merli)

There are no laws governing other technologies, all of which are a question of availability on the one hand (extremely limited for sophisticated technologies, many of which lie broken and unrepaired for lengthy periods even in the few facilities that ostensibly provide them) and the autonomy of the medical profession to make decisions on the other hand. Age "definitely enters into" many decisions to withhold or withdraw hydration and nutrition (Anon.); medical caregivers "instinctively" provide less care to the elderly and the dying (Merli). /See below, De Jure/De Facto, and Decisionmakers: Doctors and Nurses./

B. The Right to Refuse Treatment; The Right to Die

1. The Current Controversy: There is no Italian Right to Die Association, but there is a euphemistic organization for the "study of death" (thanatology). The euthanasia debate surfaces and subsides regularly, often provoked by an external event: the Quinlan case, a recommendation by the European Community Parliament (1976), a conference of physicians (held in Nizza, Italy, but organized by French Nobel prizewinners), the new Dutch law, and most recently by a proposed bill by Socialist deputy Fortuna, whose death at the end of 1985 effectively closes the euthanasia debate for the time being. (See Appendix D re Fortuna.)

The official Roman Catholic views on euthanasia are found in papal addresses, duly reported in all the press (including the left wing papers), but most fully in Osservatore Romano emanating from the Vatican. The right-wing press rarely mentions the subject, except to report Catholic teaching. Medical journals contain almost no discussion. Mori (consulted extensively for this report) writes scholarly philosophical articles on the subject, but these undoubtedly have very limited readership. And a joint Protestant Catholic left-leaning biweekly, Com Nuovi Tempi, raises the issue regularly but has a readership of only 400,500.

The debate in Italy, as elsewhere, becomes extremely emotional. Definitions get lost in the shuffle. Public speakers may attempt to draw a distinction between active and passive euthanasia, but the difference is lost in sensationalist charges of "murder." The original meaning of "good death" or "sweet death" is no longer remembered in general discussion; the difference

between "kill" and "let die," between "do" and "do nothing" or "withhold" and "withdraw" treatment are smothered in emotional debate. For those who feel that continually attempting to educate the public that the word means "good death" and not killing is a hopeless task, it is considered wiser to let the word simply take on the meaning of kill and not use it at all in connection with passive measures. For example, Barni (president of the Italian Association for Legal Medicine -- connected with the Rome-based Institute for Legal Medicine) (1984:165) suggests that these four issues need to be more clearly disconnected: abortion; non-intervention in the case of minors, the unconscious, or the incapable; suspension of reanimation therapy in patients clinically dead; and euthanasia as an active means to precipitate the death requested by a patient, or if unconscious, by his family or as otherwise decided. Barni adds that the refusal of cure (diagnostic tests or therapy) is not "euthanasia," but that refusal of cure and a request to suspend treatment should be granted only in exceptional-cases.

2. The Church's Position(s)

Those who wish to support the right to refuse treatment, or the right of caregivers to suspend treatment, tend to cite different religious documents and sources than those of another view -- the former citing Pope Pius XII in the 1950's, or the Sacred Congegation of the Faith in 1980, and the latter citing the current Pope John Paul II.

"There is no need for organizations to promote 'Good Death.' The Church has a monopoly on buona morte." (Anon. physician, a surgeon in a Vatican hospital -- where the Pope went when shot -- who argues that it is certainly permissible to withhold and withdraw in circumstances of imminent death.) The same source reminds us that in Medieval times, there were religious confraternities "per la buona morte" (for the good death). Merli agrees: "The Church is not opposed to suspension of treatment." "Pain alleviation is the primary concern for the elderly dying patient."

These physicians, and others, refer to Pope Pius XII: "Any form of direct euthanasia, that is the administration of narcotics to provoke or hasten death is illicit....One of the fundamental principles of natural and Christian laws is that man is not master of his body and existence, only its user....It is licit to alleviate pain on the one hand even if administration of narcotics has, on the other hand the double effect of shortening life, if there is no direct causal link between the narcotic and the

shortening of life" (Pio XII, 1957, emphasis added).

Again, citing Pius XII: "The fundamental principles of anesthesiology, as science and as art, and the ends it pursues do not raise objections. It combats forces which...produce harmful effects and impede a greater good. The doctor, who accepts its methods, does not enter into contradiction either with natural moral order or with the Christian ideal. He is trying, according to the order of the Creator (Genesis 1:28) to place pain under the power of man, and uses to this end the findings of science and technology." (Pius XII, 1957a) "If the same narcotics administered shorten the length of life, would it be necessary to renounce them? In the case posed, it concerns solely the avoidance on the part of the patient of insupportable pain, for example in the case of inoperable cancer...if the administration of narcotics provokes two distinct effects, the relief of pain and the shortening of life, it is licit; it is necessary, however, to see if there is a proportionate balance between the two, if the advantages of one compensate for the disadvantages of the other." (Ibid., the pope answering questions from the audience of anesthesiologists)

Speaking of reanimation to doctors and others, Pius XII declared explictly that it IS licit to interrupt the process of reanimation when a state of clinical death is established. In fact, he pronounced himself "in favor of the family which, at a certain point in verification of the irreversibility /of the patient's condition/ asks for the removal of a respirator, declaring that this can be licitly insisted upon until the doctor interrupts his efforts since there is, in this case, no direct effect on the life of the patient and is not euthanasia." (Pius XII, 1957b) (Note that the family, apparently, must persist in such requests until the doctor concurs.)

In 1980 the Sacred Congregation for the Faith issued a declaration, which analysts described as "more open" than earlier positions, calling more on personal responsibility, and noting the difference between "proportionate" and "disproportionate" measures, the latter being deemed not obligatory.

"The present text insists less than Pius XII on the idea that only God is master of life and death. Or more exactly, the Biblical idea is translated thusly: 'Every man has the duty to conduct his own life according to the design of the Creator. His life is given him as a gift which he should value, which finds its fullness only in eternal life.'...The present document, compared with earlier ones, in fact distinguishes with more

precision suicide and sacrifice in light of a great cause...the example of "Holy" Kolbe /the priest who offered himself in a concentration camp in order that Jews be spared — not yet sainted at the time of the citation/... On the other hand, noteworthy is the firmness shown in condemning suicide and euthanasia if done for existential reasons....It is not a question of a fatalistic or painful conception of death. The document does not deny the tragic aspect of the last moments of earthly existence, but recalls Christians of today to that which they've forgotten, that this is above all an encounter with Christ, entrance into a new communion with God....Suffering is not, in itself, a savior, redemptor....It should not be considered an inevitable element of the human condition....Prudence requires the attenuation of suffereing. A heroic attitude is laudable....Concretely the choice is rarely between pain and non-pain. Even helped by medical means, the sick (especially the dying) person lives in a situation of depression, humiliation, slow and successive cancellation....Fighting against pain, using drugs that are progressively potent, presents the risk of shortening the elderly person's life. But Pius XII referred to the double effect principle. It is possible to tolerate such a risk if it is not wanted for itself and if the risk is run only indirectly....The classic documents distinguished between "ordinary" and "extraordinary" therapy; many moralists have renounced this criteria which is very relative. They go less far than many doctors who, in line with their profession (to protect life at any cost) risk prolonging the life of larvae....The present declaration poses a series of four solutions, concrete, for precise situations....The first is that of the use of disproportionate therapeutic measures (paragraph IV). In one environemnt the measures will be ordinary, in another extraordinary. It is a secondary aspect; that which counts is to know if there is proportionality between the measures used and other aspects of the sitaution: the quality of life which it is possible to attain, taking into account the status of the sick person and his physical and moral resources.' It is possible to legitimately judge, in certain cases, that '<u>the investment in instruments and in personnel is disproportionate to the predictable results, and that the measures set in motion impose on the patient discomfort or suffering out of proportion to the benefits which he could receive from them</u>.' In a certain sense, one could talk of a conflict of duties and of duties with rights...but taking into account that in any case there is no transgression of a moral minimum absolute as in the case of direct euthanasia

or abortion....It is not a question of giving to the individual conscience the right to determine good from bad....The conscience (of doctors, of the patients, and of their relatives) works in continuity with moral obligations, but also with 'certain aspects of the case.' One sees without doubt the danger of certain possible abuses, but on the other hand a large place is given to 'personal responsibility.'" (Delhaye 1980:795-798 emph. added)

It might be noted -- by this non-theologian -- that the issue of personal freedom of conscience is one of major difference between Catholic and Protestant teaching, as is the fundamental basis of whether God or the person is "master" of his body and destiny.

The present pope, generally viewed as very conservative on a number of issues, has not unexpectedly taken a more restrictive stand than his predecessors on the issue of euthanasia. In October 1984, Giovanni-Paolo II reaffirmed opposition to abortion and euthanasia in a presentation to the congress of Italian Anesthesiologists' Association. "The Church, as you know, is not for the support at any cost of pain. The Church considers licit action which tends to reduce or eliminate physical pain....However, although confirming this principle which has its roots in the Bible, we exhort Christians and all believers to tolerate suffering in union with Christ....In suffering, in fact, the believer finds the strength to purify himself and to cooperate in the salvation of his brothers." (John Paul 1984)

Most recently, John-Paul addressed a congress of scientists, October 1985. It is interesting to see the different emphases given by the press: while the Italian press referred to the Pope's re-condemnation of euthanasia, the International Herald Tribune trumpeted his support for "death with dignity." The casual reader might think that this means passive euthanasia, or painkillers that both alleviate pain and may also hasten death. But a more careful reading (particularly of the entire text which we obtained in English translation from the Vatican) shows that "dignity" has many interpretations, and that such measures are NOT included in the definition of dignity as used here. John Paul again notes that suffering is part of normal human existence, and that when one is about to encounter Christ one should not be drugged to unconsciousness. "According to the Pope, to confront the problem of euthanasia, it is necessary to begin with two presuppositions: life is a value and death a natural event. From this we derive

that life cannot be interrupted, not even to alleviate the suffering of a painful death, and that death cannot be avoided since it is part of human experience. It is correct that scientists and doctors dedicate themselves to prolonging human life, and for means to better it, but not to overcome it. 'Only God' said the Pope 'is master of life.' Stern judment also for those who help the sick to confront death in an unconscious state, because thusly they impede them from encountering Christ in full consciousness. The best thing, according to Woytyla, is that the sick person suffer with patience and at the end die in his 'natural' time. Every attempt, every cure which tries to alleviate pain of this passage goes against the 'natural' condition of human life. One can resort to narcotics only if the patient does not have the 'moral force' to tolerate the suffering." (ADISTA 1985)

In the same address, John-Paul declares that it is permissible to use experimental technologies, even if they carry some risk, when more ordinary methods fail or are not available, and it is also possible, with the patient's consent, to terminate such extraordinary measures if results fall short of expectations. Account must be taken of the patient's wishes, those of his family, and the doctor's advice. There is no obligation to initiate such extraordinary, possibly risky, methods of care. He thus appears to be coping with the difficult definition of what means are extraordinary and which are ordinary by referring to experimental, potentially risky methods and declaring these non-obligatory and interruptable, while making no reference to the interruptability of other measures. (Osservatore Romano 1985)

3. Legal Issues: Defining the Moment of Death; Clinical Death

It is not by chance that we have placed religious considerations before legal ones in this report, for laws, court decisions, as well as common custom are heavily influenced, if not dictated, by Church teaching.

Since there is no Italian law specifically forbidding euthanasia, other than the wider law concerning homicide, one must look to the law on transplants for word on defining death. (As noted above, there are few transplants in Italy, Merli of the Institute for Legal Medicine points out that the transplant law protects physicians from prosecution, rather than regulating their behavior.) There have been efforts to codify transplant law for over 25 years (Merli), with little success. The law of 1975 Number 644 has now been in effect over a decade; in 1983 a revision was proposed, which is under discussion in the Senate. While doctors seem to

wish to keep the law -- or rather the non-law -- on euthanasia vague, leaving them scope for "the exercise of common sense, not like you Americans with a lawyer at every bedside," there is considerable support for clarification of the transplant law -- in order not to restrict, but to further protect, physicians. The 1975 law refers to measurements of heart, respiration and brain activity: two circumstances are distinguished (Merli): when the heart stops, it is permissible to enter the body 20 minutes later to remove surviving tissues. If, however, it is the kidneys, heart, or lungs that are to be taken for use in transplant, then a flat electoencephalogram for 24 hours is sufficient. Article 5 refers to a committee composed of one legal doctor, one anesthesiologist for reanimation, and one neurologist specialist in electrocephalographia. The committee must observe the patient for 12 hours to determine the moment of death. The proposed new law -- taking into account advances in neuro science, would require one doctor to determine if brain function has irremediably stopped. The organ donor "must be surely dead, but not too much." (There is little chance of a mis-translation of this charming phrase, since the words are all quite simple. Perhaps a cultural gap exists, but my collaborator could also not fathom what "not too dead" really means -- except the obvious interpretation that the heart must still be viable even if the patient is dead in a legal sense.) The proposal also refers to brain death, or flat brain waves for only 3-4 hours, even if heart and lungs are still functioning, leaving to medical science and the doctor's conscience the decision, taking into account "the particulars of the situation." (These, presumably, would include the patient's age, and possibly his potential "quality of life.") The bill seems unlikely to pass.

Meanwhile, between the 1975 law and the present proposed law, in 1977 there was a presidential decree (NUmber 409) which contained seven titles concerning the ascertainment of death and authorization for removal and transplant, consent, referrals to regional centers, etc. -- based on the recommendations of the European Council that transplants be permitted if no contrary will has been expressed by the donor.

After days of front-page lamentations in all the major newspapers, the way was finally cleared for performing heart transplants in Italy in eight specially equipped centers. The delay stemmed from "bureaucratic bungling" (refusal by the health minister to sign the final permission), and resulted in headlines about one patient who died while waiting, and another whose

identified donor was finally buried without removing his heart. (This patient, however, became the first to receive a new heart when the bureaucracy finally moved and another suitable donor was found.) Recent headlines carried the story of the 8-year old whose family had collected $65,000 so she could go to America for a heart transplant; the money will be returned, since she received the heart of an Italian 7-year-old instead.

4. Legal Issues: De Jure vs. De Facto; Physicians' Attitudes

Italy, as elsewhere, has examples of yawning gaps between law and actual practice, or, where law is fuzzy, of wide differences in interpretation. Most of these discrepancies in Italy can be summed up in one sentence: the doctor decides.

Two strongly divergent opinions can be cited by prominent physicians, both important operatives at Gemelli Hospital -- Vatican-run, considered probably the best hospital in Rome, associated with Catholic University. Our anonymous consultant says, for example: "Doctors will do everything to save a young person who's had an accident, but for a tumor in an old person, we only try to minimize the pain." "If a terminal patient is awake, we never unplug him, but water might be substituted for nutrition in the tube." "It is not only age that determines decisions, but potential quality of life." "Consult the patient? Not really. Consult his family? Why? The doctor decides." From the same hospital, professor Corrado MAnni, director of the Institute of Anesthesiology and Reanimation of the Universita Cattolica del Sacro Cuore, maintains that no one ever asked him to help him to die, that euthanasia means "to give death" and is therefore always homicide, and that to suspend treatment is equivalent. He says that modern medicines are now available that will alleviate pain without hastening death, so the "double effect" argument is now moot. If the doctor does NOT insist on every possible therapy, he maintains, then patients will not trust their doctors. Therapies that may have been considered extraordinary and risky 50 years ago now have a better chance of success today and should be pursued; even if they don't succeed in curing the present patient, their experimental use will benefit future generations. He is certain that the majority of Italian physicians agree with him, and that his views are in no way based on Catholic teaching but rather on 30 years of professional experience. (Osservatore Romano 1985A) Despite their apparent difference of opinion on the initiation of extraordinary means, or their interruption, these two physicians have in common the opinion that the decision belongs to the physician, not to the patient or his family.

Merli, director of the Institute of Legal Medicine, comments on this and related issues:

> It is 'instinct' for the doctor to treat an older person differently from younger ones.
>
> There has been a gradual evolution in practice toward greater willingness on the part of hospital personnel to withhold extraordinary treatment or to unplug the plugs when the patient is irreversibly comatose.
>
> Passive euthanasia is, de facto, widely accepted, although there are conscientious objectors there too.
>
> No one technically has the right to unplug, but they easily do so. Doctors do. Nurses will refuse, for fear of its being considered out of the range of their competence.

Many publications use a hard-to-translate expression: accanimento terapeutico (the "cane" referring to dog) -- dogged therapy, or therapeutic doggedness, or tenacity -- i.e., hanging on, bulldog style, continuing with heroic measures, regardless. The "gradual evolution" referred to above by Merli includes a growing recognition that such bulldoggedness is not necessary.

There are no laws prohibiting the gradual increase of pain killsers, bat as seen above there are controversies within the Church as to when they may be licit; Merli indicates that no doctor would fear a lawsuit if he were to gradually increase the dose of morphine, for example.

On the subject of cost, we find two quite different views: Mori says that "of course costs matter; as long as the state pays, there's no limit to the life-prolonging experimentation that physicians and technicians will engage in", while Merli also says "Of course costs matter" adding, however, that "it's not possible to do everything for everyone, so plugs get unplugged to make room for the next patient."

The most striking comment of all was by Merli, who likened the Italian hospitals to a battlefield, commenting that "medicina di guerra" (wartime medicine -- i.e., triage) was being practiced there, abandoning patients who are going to die anyway.

Mori the ethicist (1985) suggests that opposing views on euthanasia are furthur apart theoretically than in practice. That is, there is broad general agreement on the need to lessen suffering and -- with some exceptions such as Manni, cited above -- on the non-necessity to pursue "extraordinary", "heroic", "disporportionate" therapies.

5. The Decisionmakers: doctors, families, patients -- surrogates

According to Article 32 of the Italian constitution, no one can be forced to accept a particular health treatment unless it is in the public good, as in the case of vaccinations; the law is intended to prevent experiements on the human body. Exceptions, of course, include the court-ordered transfusion for a Jehovah's Witness minor in the event it is denied by the parents. In the case of the recent heart transplant, the 8-year old patient and her family are Jehovah's Witnesses; the parents made the physician and his team promise not to resort to blood transfusions in the course of the procedure, which happily was accomplished without the need for blood. The newspaper accounts do not further discuss whether the court might have intervened, over parental objections and over the doctors' promises to let her die rather than resort to a transfusion. Merli says "If someone wants to die, they can simply refuse treatment." Attempted suicide is not punishable. The patient merely signs a non-consent form for intervention. Consent forms are ostensibly routinely signed for all surgical interventions, but in practice are frequently omitted. A physician in Turin has recently had his license suspended -- no further legal action is anticipated -- because a 16-year-old abortion patient died following the use of a highly experimental technique that neither the patient nor her family knew was to be used.

A parent cannot decide to subject a minor to non-emergency or non-essential intervention, such as a nose job; the minor's will, in such a case, takes precedence ("leave my nose alone"). In the case of conflict, as regards abortion, for example, the minor may override parental refusal of treatment through recourse to the courts.

Barni (1984:165) contends that the refusal -- on the part of a patient or surrogate -- of care is normally to be condemned, but is not morally wrong if the patient refuses a particular therapy and if it is objectively or subjectively considered extraordinary or unusual.

While there is some mention in the press of the concept of Living Wills, usually with reference to models in other countries, these are apparently unacceptable both to the majority of the medical profession, who would find their decision-making role threatened, and by "the Jesuits" who would argue that man is not master of his body and therefore not in a position to dispose of it in such a way...giving that responsibility to God's surrogate in a white coat.

Barni (1984:170) suggests that not only can a patient refuse treatment, but that a physician who persists in medical or surgical treatment against a patient's will is engaging in unacceptable conduct according to medical ethics and may even be bordering on illicit conduct punishable by penal law (the closest anyone seems to come to suggesting that battery or privacy issues may enter in). There is, by the way, no Italian word for "privacy," although in recent years the borrowed word "privatezza" has entered the language.

Despite the unacceptability of a Living Will by the majority of the medical profession, a well-known Milan physician may be said to have declared his own such Will, orally: E. Malan, director of the Surgical Clinic of the University of Milan, a propos exceptional interventions in the case of Generalissimo Franco, said "As doctor and surgeon, I must say that such a way of proceeding is justified and right. As a man I could have my doubts about certain things. For myself, perhaps, I wouldn't want to be treated in a similar way; I would prefer to exit tranquilly. I have already told my assistants that if something happens to me, not to jump all over me /taking exceptional measures/." (Malan 1975)

There are two types of incapacity: natural (as in the case of a minor) and pathological (as in the case of mental illness). Article 54 of the penal code states that in case of necessity, an intervention is permissible even against the will of the patient, to save the patient's life. This is now under discussion. Who decides the patient's competence? The family, according to Merli, although there are no laws to say so. The court intervenes only in the case of refusal: if the patient is deemed competent, even a court order cannot force treatment.

There are generally accepted procedures for deciding who takes responsibility for the incompetent patient: first the husband or wife, then father or mother (first-grade relations), but this is merely custom, not codified. If there is a conflict among them, they can go to court, but this is most rare (Merli).

In many cases, the physician will "consult" the patient's family, but in such a way that they virtually have to follow his advice (Mori).

The decision-making authority of the physician seems to be barely challenged. A Committee on Euthanasia of the Institute for Legal Medicine has been formed, announcing that it will meet...a year from now! They seem in no hurry to settle, or even discuss, the issues. They want clarification of

the transplant law, but not clarification of a euthanasia law, such as that proposed by Deputy Fortuna (see below). Limited hospital space, and a situation of wartime medicine, result in daily decisions to withhold or withdraw treatment from the terminally ill, but "it's nowhere written and no one discusses it." (Merli) There are no hospital committees to decide; the doctor decides, and then "advises the family; it is easy to get their acceptance of his decision." (Anon.) "Decisions are left to the good sense of the physician; if he sees that the patient is incurable, he will not massage the heart. The doctor is more afraid of tattletale nurses than of the patient's family." (Anon.)

6. Proposed Law on Euthanasia

Between the penultimate and this final draft, the father of the proposed euthanasia bill died (see Appendix D), which effectively kills the issue, according to most observers. Socialist deputy Fortuna's proposal was based on the 1976 recommendations of the Council of Europe (#779) which deal with reanimation, pain abatement etc. It does NOT deal with active euthanasia. It was intended to "assure dignity of life and regulation of passive euthanasia." It would dispense physicians from subjecting to life-sustaining technologies everyone in an irreversible terminal condition, unless the patient consciously consented to their use. Terminal condition was to be determined by a physician designated by the local health unit, and he should verbally communicate to the relatives of a patient over 16 or to a minister of his religion or to the patient himself or his direct or indirect line of antecedents or descendents (up to the second grade of relation); these persons should all be over 16. If any of these wants to oppose the termination of treatment, they should do so within 12 hours. Even in this case, the President of the Court, after hearing the reasons of the person opposed to suspension of treatment, and to the physician, can authorize suspension of therapy.

Only the Radical party seemed interested in moving the bill to discussion (not even Fortuna's own party, the Socialists, were eager to back it, as in the case of the divorce and abortion bills he previously sponsored, see Appendix D). Merli points out that law cannot go ahead of culture; while brain death as a concept has now entered the common culture in Italy, public opinion is still not "ready" even for a rational discussion of the issue.

In an opinion poll, the family of a paraplegic would answer differently from others in the general public, on questions regarding euthanasia (Merli).

In a recent poll, however, a large majority of Italians (see Appendix E) were found to favor what might be termed "passive euthanasia" and a similarly large majority were opposed to "active euthanasia," although support for the former was interpreted on the basis of responses to questions that did not actually use the term "euthanasia." (We might expect quite different response rates had the term been used, in fact.)

The strategy of the Fortuna bill was to introduce the proposal, then let it "cook" for a few years while public opinion is educated to the meaning of passive euthanasia, or while the issue is discussed in terms that omit the use of the tabu word, and only then reintroducing the bill to the legislature.

IV. LIABILITY

There seem to be differing perceptions as to whether there are few or many malpractice cases in Italy, and no way to determine just how many. Surely bringing suit is far less common than in the US. The Institute for Legal Medicine is involved in at least 100 a year, but they do not represent all Rome or all Italy, where Merli believes there may be "thousands" annually. (Common perception, however, is that there are virtually no such cases; an Italian medical sociologist stated categorically "There are practically none in Italy," and our informal contacts confirmed this public view, which may well explain why there ARE so few, it not being known to most people that malpractice suits can in fact be brought.) Our anonymous surgeon informant, for example, believes such suits are "very rare" and that physicians have "little to fear." He cites the case of a husband whose wife died in childbirth; the husband was accused by friends of being mercenary because he suggested a civil case to collect damages. He says it is difficult to find doctors willing to testify against other doctors, but Merli says it is not difficult at all. Mori says a case is brought only if a death is involved. (See Appendix F, the brief account of a physician who went to prison for a year for having refused a cesarean section to a woman whose neonate died -- ostensibly from lesions suffered during delivery.) Most vulnerable to suit are orthopaedists and obstetricians.

Most malpractice cases that are brought do not involve overtreatment, but error in diagnosis and mistreatment. Nurses are also subject to suits, especially if they function outside their defined "sphere of competence." (A computer search in the Court of Assizes, using a variety of keywords, did not turn up any malpractice cases. The case list, however, when

consulted for cases on "omicidio del consenziente" -- assisted suicide, or active euthanasia -- turned out to be almost entirely all abortion cases!

While doctors may feel immune to threats of malpractice, institutions of health care are subject not only to legal prosecution but a veritable hailstorm of journalistic criticism. Our anonymous informant points out that the post office and trains are also in abominable condition, but that the health care system is an easier target for journalists, particularly those motivated by political considerations -- although we have found biting criticism in papers from the far left to the far right. (Criticism of health care in Rome could, until recently, be interpreted as criticism of the former Communist government; it will be interesting to see if the current Christian Democrats can either improve the system or at least turn away journalistic accusations. One nurse of our acquaintance insists that everything worked better, especially the hospitals, under the Fascists.)

Apart from political considerations, and whether it sells more newspapers to attack the health care system or the way the post office treats its clients, it is widely acknowledged that the dream of universal free health care of a high standard is far from realization, and that practice within that system -- with regard to the subject of this report, as well as more generally -- departs widely both from the prescriptions of the legislature and from the official teachings of the Catholic Church.

REFERENCES

Anonymous physician -- a surgeon at Gemelli hospital.

Barni, Mauro. Right to Die (Diritto a Morire) and other chapters in dell'Osso, Giuseppe. Responsabilita e Progresso Medico. Milan: Giuffre, 1984. (Barni is on the faculty of Jurisprudence, University of Siena, and president of the Italian Medico-Legal Society.)

Crociella, Carlo, director, Social and Cultural Commission, House of Deputies, personal communication.

Delhaye, Monsignor, secretary of the International Theological Commission. Comment on the declaration by the Congregation for the Doctrine of the Faith. La recente dichiarazione della Contregazione della Fede sull-eutanasia. Attualita, October 1980, 795-798.

l'Espresso. Lamento di un presidente pentito. 21 April 1985, 28-32.

il Giornale. 15 December 1985, p. 2.

Istituto Centrale di Statistica. Le Regioni in Cifre, 1985, Rome.

Istituto di Ricerche sulla Populazione. The Italian Population: an Overview; Demographic Profiles of the Italian Regions, June 1985.

John Paul II, in Osservatore Romano 5 October 1984 (Vatican newspaper).

Malan, N. Perche resiste? (Why resist?) in Il Giornale Nuovo, 9 Nov. 1975, p. 1, cited in "Diritto di Morire?" (Right to Die?) by Giacomo Peric, Aggiornamenti Sociali, December 1975.

Manni, C. "La battaglia quotidiana della terapia intensiva" (The daily battle of intensive therapy), Osservatore Romano 20 April 1985, p. 6. (Professor Manni is director of the Institute of Anestheiology and Reanimation of the Catholic University of the Sacred Heart, and of Gemelli hospital.

Merli, C. Director, Institute for Legal Medicine, Rome. Personal communication.

Mori, Maurizio, fellow at the Institute of Philosophy and Sociology of Rights, University of Milan, 1985 personal communication.

Mori, Maurizio. Su alcuni problemi concernenti l'eutanasia (On some problems concerning euthanasia), Transizione 3/85, and Contributi per la discussione, Center for Research and Training in Policy and Ethics, Milan, 6 November 1985, Euthanasia, a clarifying analysis and ethical proposal. (1985a)

Natale, Prof. M. Crescita. "dell'Invecchiamento e Implicazioni Socio-economiche dell'Emarginazione dell'Anziano. Il Nuovo Boll. di Farma-cologia Clinica, May-August 1981, 171-184.

Osservatore Romano 20 April 1985, 6-7. Series of articles under the general heading of Euthanasia, Culture of Death.

Pius XII, Discorso ai partecipanti al IX Congresso della Societa Italiana di Anestesiologia, 24 February 1957.

Pius XII, Tre questiti religiosi e morali concernenti l'analgesia, 24 February 1957 (1957a).

Pius XII, Risposte ad alcuni importanti questiti sulla 'rianimazione', 24 Novebmer 1957. (1957b)

Also consulted in preparation of this report, though not cited directly in the text:

Bangert, Diederik. Il diritto a una morte serena (the right to a serene death). In the Netherlands even the Christian Democrats are in agreement. Parliament will decide soon. Il Messagero, 15 September 1985, p. 25.

Wojtyla condanna l'eutanasia. E un crimine. (Wojtyla condemns euthanasia. It's a crime.) La Repubblica, 22 October 1985, p. 16.

Marroni, Stefano. Entro cinque anni rivoluzioneremo la sanita romana. (Within 5 years we will revolutionize Roman health care.) La Repubblica 29 December 1985, p. 26.

Saulino, Felice. Arrivano gli aumenti di Capodanno. (The increases of the New Year are coming.) La Repubblica 27 December 1985, p. 3.

Dipartimento Affari Sociali e Culturali, Camera dei Deputati. Servizio Studi. I Trapianti Terapeutici, Feb. 1983.

Istituto di Ricerche sulla Populazione. Un quadro di sintesi della situazione demografica italiana. June 1985.

Comitato Nazionale Italiano sui Problemi della Terza Eta. Rapporto sulla Condizione degli Anziani. No date.

Camera dei Deputati. Il Disegno di Legge per la Finanziaria 1986.

Burgalassi, Silvano. La Condizione Anziana. Civitas, 1-2/1984.

La Politica per gli Anziani. 1/81, unpublished.

Gatteschi, Donatella. Servizi Socio-Sanitari e Difesa degli Anziani. Rome: La Nuova Scientifica Italiana, 1980.

Pavone, Marisa and Francesco Santanera. Anziani e Interventi Assistenziali. Rome: La Nuova Scientifica Italiana, 1982.

I Diritti dei Malati e dei Morenti (the Rights of the Sick and Dying), mimeo from a Protestant Commission, 6 August 1982 (chiese evangeliche valdesi e metodiste).

APPENDIX A: National Health Service

The national health service constitutes the entire health structure which the State, the regions, the localities place at the disposition of their citizens for the care of their health and prevention of disease. Inscription in the SSN (NHS) is automatic for all citizens already enrolled in mutualaid entities and thus in possession of a card. Citizens however who have never enjoyed any form of assistance, are enrolled in the SSN by choosing a doctor of choice. The citizen who needs a medical visit should go to his own doctor of choice -- to his clinic/office or in case of need in a home visit. The ambulatorio (clinic) should be open for 5 days a week, with opening hours that assure adequate care. On Saturday it is not obligatory for the doctor to open the office, while he should deliver home visits until 2 PM. Home visits are also free, but subject to the following rules: if the request is made before 10 AM, the doctor's visit must be made during the day. In the case in which the request is made later, the visit must occur before noon of the following day. The doctor of choice is obliged to make a home visit, also on Saturday, if the request is made before 10 AM. From 8 PM until 8 AM weekdays and from 2 PM to 8 AM Saturdays and Sundays (i.e., till 8 AM Monday), for urgent cases a Service of Medical Guard is in operation in every area of the country. Also in these cases the care is absolutely free.

Hospital services: where the citizen needs hospital care, on the proposal of the caring physician and providing the enrollment card, he can obtain care without charge in: public hospitals, with just the referral by the attending physician; in institutes and licenced nursing homes (licenced by the Region) with the referral of the attending physician and the authorization of the USL (local health unit).

Private licensed Nursing Homes (not necessarily for aged): for these places the expence of a bed stay is the responsibility of the citizen and he can request partial reimbursement, in the degree established annually within his region. Users must go to the USL.

Specialist care: In case of specialist visits or diagnostic tests (analyses, X-rays) the citizen can go: to the policlinics of the mutual entity (former entities, now USLs), to the specialist offices of all public hospitals, to the licensed specialty clinics. In the first two cases all that is needed is the request of the physician of choice and presentation of the enrollment card; no other authorization is necessary. The request of the physician is not necessary for the following specialist visits: pediatric (for those who do not already have a pediatrician of choice), obstetric-gynecologic, odontriatric. It is possible to report to licensed specialty clinics when other structures are not in condition to satisfy the request in a short time.

Medicines and pharmaceutical help: Only the doctor of choice and the specialist can prescribe drugs to the citizen who requests them or after a medical visit. The prescription should be placed on a form and can be used within 10 days in the pharmacies of the Region indicated on the prescription. Some of the drugs commercially available are furnished free to the citizen who presents a medical prescription. For other medicinal specialties, however, the user is obliged by law to pay a small sum directly, the so-called "ticket", in proportion to the cost of the medicine.

What is the USL (Unita Sanitaria Locale): USL means Unita Sanitaria Locale. It means a complex of buildings (policlinics, hospitals, consulting offices etc.) and personnel who work there (doctors, administrators, pharmacists, nurses, analysts etc.) who can furnish the citizen a complete, free assistance. The USL depends directly on the individual or associated Comune. All Italian citizens present in the territory of the Lazio (Rome) region have the right to be assisted by the Sanitario Servizio.

Choice of the Doctor of Choice (literally, doctor in whom you have trust): To obtain many of the services of the SSN the citizen must choose a doctor of trust.

APPENDIX B:

Health: Goodbye Services; Nearly Everyone of Us Will Pay

Paese Sera Monday 30 September 1985

From a full-page article on the Battle in the Senate, beginning Wednesday, including education, transport, health etc.

Dear Tienamocelo, our family doctor. Because his service will be one of the few free services that the state will offer to the citizen. The health sector in fact is the most hit by the spending cuts predicted for the 1986 budget. The State in fact, will limit its free intervention only to those pateints in hospital, to the family doctor, and for those with a family income very low, at the limits of survival, that is 11 million lire a year (about 850 thousand a month). The certification of income, will be conducted by the city government which, will be called to a co-responsibility. Above 11 million, citizens will be asked to put their heand into the wallet: a prescription will cost 2000 lire (about double the present-day ticket), while tickets for medicine, analysis, and thermal cures and specialists will rise to 25%. But that's not enough, the health union and the regions, in fact will have the right to apply supertickets for the upper income category, for both direct and indirect services (the former currently receive services without paying, the latter pay and are then reimbursed).

SANITA'

Assistenza addio pagheremo quasi tutto

TIENAMOCELO caro, il nostro medico di famiglia. Perché la sua assistenza sarà uno dei pochi servizi gratuiti che lo stato offrirà ai cittadini. Il settore della sanità è infatti il più colpito dai provvedimenti di tagli di spesa previsti con la finanziaria '86. Lo Stato infatti, limiterà il suo intervento gratuito solo ai ricoveri e prestazioni ospedaliere, al medico di famiglia, appunto, e nei confronti di chi ha un reddito familiare basso, al limite della sopravvivenza, e cioè di 11 milioni l'anno (pari a poco più di 850 mila lire al mese). L'accertamento del reddito, ai fini dell'erogazione gratuita dell'assistenza, sarà demandato ai Comuni che, in tal modo, saranno chiamati a una corresponsabilità. Oltre gli 11 milioni, i cittadini saranno chiamati a mettere mano al portafogli: la ricetta costerà 2000 lire (circa il doppio dell'attuale ticket), il ticket su medicine, analisi, e cure termali e specialistiche salirà al 25%. Ma non basta, Usl e Regioni, infatti avranno la facoltà di applicare «superticket» oppure tramutare — per le fasce superiori di reddito — l'assistenza diretta in assistenza indiretta. Lo stesso regime, del resto, previsto per le famiglie con reddito lordo annuo superiore ai 30 milioni, che saranno chiamate a pagare totalmente ogni prestazione, salvo ricevere un parziale rimborso. Ancora: saranno aumentati i contributi malattia sia a carico del lavoro dipendente (l'1,35% della retribuzione imponibile per i lavoratori e il 9,6% a carico della azienda) che di quello autonomo (il 9% del reddito lordo imponibile). Con tutte queste misure — che, di fatto, smantellano lo Stato sociale, favorendo invece un parallelo sistema assicurativo privato e pagamento, il governo conta di risparmiare 2 mila miliardi.

By Law, These are the Duties of the Unita Sanitaria Locale (Rights of the Handicapped), from La Repubblica October 1985

With medical documentation, parents can request recognition of invalidism of a minor under 18, which carries the right to a) total exemption for payment of medicines and care of the sickness, b) free provision of prostheses, orthopaedic shoes, wheelchairs, and whatever technology is currently available to stimulate the capacity for recovery or betterment of the quality of life. The law also guarantees: physiotherapy and specialist visits (home visits if the handicapped cannot walk), free summer trips. In case of total invalidity, the family has the right to a monthly check of about £250,000 ($150) until the child is 18, when it changes over to a social pension.

Molti i diritti dei malati

Per legge questi sono i compiti delle Usl

10/85

ROMA *(e.d.a.)* — Ecco un breve elenco dei diritti all'assistenza che lo Stato riconosce al soggetto portatore di handicap, alla sua famiglia e le procedure necessarie per ottenerli. Le strutture a cui fare riferimento sono il Servizio Materno-Infantile e l'Unità Territoriale di Riabilitazione (Utr), organismi che devono essere presenti per legge in ogni Usl. In questa sedi sono svolti, o richiesti per essere eseguiti in ospedale, gli accertamenti clinici necessari per valutare la gravità della menomazione e per decidere le cure necessarie.

Con la documentazione medica in mano i genitori possono inoltrare la domanda di riconoscimento della invalidità civile presso il Servizio Invalidi Civili della Usl di residenza. Tale riconoscimento dà diritto a: 1) esenzione totale dal pagamento dei farmaci necessari al trattamento della malattia; 2) fornitura gratuita di protesi, scarpe ortopediche, carrozzine e di qualunque ritrovato messo a punto dalla tecnologia in grado realmente di stimolare le capacità di recupero dell'handicappato o di migliorarne sostanzialmente la qualità della vita.

La legge poi garantisce agli handicappati fisioterapia e visite specialistiche di controllo da eseguire presso la Utr o presso centri privati convenzionati (se il paziente non è in grado di camminare ha diritto a tutte le prestazioni a domicilio); partecipazione ai soggiorni estivi gratuiti organizzati dalla Usl. Infine, nei casi di invalidità totale, la famiglia ha diritto ad un "assegno di accompagno" mensile che ammonta a circa 250.000 che sarà versato sino al 18° anno d'età, momento in cui subentra la pensione sociale.

Il piccolo Antonio Di Mario ha mai usufruito interamente di questi suoi diritti?

APPENDIX C: Therapeutic Tenacity: the Case of Calvino

In a recent example of the irreversible coma of a famous person (writer Calvino), public statements acknowledging the irreversible state nonetheless pointed out that "the medical team has never ceased an instant in its efforts to save him." ("Italo Calvino is at the end of his life. His heart, effectively continues to beat, but the brain of the writer, at the end of another dramatic night, is sliding toward a sleep from which he will never reawake: "coma irreversible," is the verdict of the doctors who, it is not rhetoric to say, have not ceased an instant to fight to save him.")

La Repubblica 18 September 1985

Siena, uno spasmo cerebrale fa cadere le speranze di salvare lo scrittore

Calvino in agonia Verdetto dei medici "coma irreversibile"

dal nostro inviato La Repubblica Siena

SIENA (a. a.)— Italo Calvino è in fin di vita. Il suo cuore, valido, continua a battere, ma il cervello dello scrittore, al termine di un'altra drammatica notte, è scivolato verso un sonno che non avrà risveglio: «Coma irreversibile», [illegible]

E' stato un nuovo spasmo cerebrale a far cadere ogni speranza: una violenta, improvvisa, contrazione delle arterie che irrorano il cervello. Pochi istanti e il tessuto cerebrale viene investito da un vero e proprio infarto, contro cui non c'è rimedio possibile.

Il corpo dello scrittore ormai privato della coscienza è ancora in vita, ma i suoi occhi non reagiscono più alla luce; le braccia sollecitate si abbandonano ad articolazioni passive. Solo le gambe si muovono ancora «in flessione» comandate da una reazione corretta agli stimoli. E questo fa dire ai medici che non tutto il percorso è stato compiuto: vi saranno ancora ore, forse giorni di attesa.

E' toccato al professor Antonio Stanca, primario del reparto di rianimazione, comunicare a Chichita e a Giovanna Calvino, la moglie e la figlia dello scrittore, la notizia dell'improvviso peggioramento.

Chichita Calvino deve aver fatto appello a tutte le sue forze. La si è vista arrivare all'ospedale, intorno alle 11 del mattino, appena scossa da un lieve tremore, evidentemente sapendo o presagendo le brutte notizie. Dopo mezz'ora di colloquio a quattr'occhi con il primario si è affacciata sul corridoio del reparto. C'erano la figlia e pochi amici ad aspettarla. Poi, parlando in spagnolo lei, argentina dagli occhi europei, assorti e dolcissimi, si è rivolta al gruppetto dei familiari come se dicesse parole di sprone e di incoraggiamento. Quindi sono scomparsi dietro le porte metalliche dell'ascensore.

La crisi è arrivata alle quattro del mattino. I medici del reparto di rianimazione ne hanno subito notato i segni gravi, inconfutabili. Tanto acuti erano i sintomi, racconta il professor Stanca, che si è pensato ad una nuova emorragia. Invece si era trattato di uno spasmo delle arterie cerebrali, il secondo dopo quelli che da mercoledì e giovedì della scorsa settimana era venuto a spezzare un decorso postoperatorio che sembrava promettere bene. Lo spasmo è la complicazione più temuta, ma anche più frequente in questo tipo di malattie: ogni intervento clinico è praticamente inutile. Solo l'elasticità dei vasi (tanto maggiore, quanto più giovane è il paziente) può in certi casi indurre una risposta naturale che sovvenga la situazione. Questa risposta nel caso di Calvino non si è avuta. Anzi lo spasmo ha provocato un [illegible] e poco a poco quest'attività automatica del cervello è stata coinvolta. L'intervento dei medici ha cercato sempre di [illegible] l'effetto di bloccare la crisi. Ma il danno prodotto dal [illegible]

APPENDIX D: The Man of Civil Rights: Fortuna is Dead, Father of the Divorce Law

He never ceased to fight, to convince, to battle. Everyone will say of him, now that he's dead, that he was the father of divorce. True, but he was something more, he belonged to that faction of the Italian left which, after having taken up arms against fascism, then left he Communist Party with anger and bitterness following the Soviet repression of the workers' revolt in Budapest in 1956. Fortuna became a socialist and "nourished" the liberal-radical sector....Even in the socialist house he had his problems. The PSI remained aparty structured in the Marxist-Leninist style, aggravated by the same type of para-Catholic moralism that en-encumbered the Communist party....the left was frozen by rites of ortho-doxy.

Thus to be in favor of dicroce, a layman, anti-clerical, was to live in a condition of terrible discomfort.

Fortuna was elected deputy in 1963 and the law which introduced divorce into Italy was approved in December 1970. Three years later he proposed the first law to legalize abortion. By then the door to civil rights was broken down and subsequent referenda to abbrogate them failed. On the wave of the divorce victory of 1975 Italy experienced a turn to the left with the beginning of that tumultuous redistribution of consensus that redesigned the entire Italian political scene.

At the beginning Loris Fortuna was alone, or nearly so: intellectuals of the liberl left supported him. Divorce was seen negatively not only by the Catholics; many communists and a good aprt of the socialists also frwoned on it. It was in style to justify this aversion by referring to the terrible danger that it would fracture the country. The major parties, however, had to recognize that the present-day country was galopping along by itself with the worker and student movements demon-strating how wide was the gapb etween represented and representative.

Thus it was that the divorce law passed, but as a product of negotiation, compromise, exchange and some underhandedness. The country did not break apart. The abortion law was no less dramatic; it raised different ethical issues, more agonizing but it also went along. The big parties of the masses stopped grumbling. Peasant-Mediterranean Italy became forever industrial-European Italy, also thanks to divorce and the nearly-solitary battle of Loris Fortuna and his few companions.

The article continues to outline his many other Parliamentary roles, but not a word with reference to his recent proposal on euthanasia.

La Repubblica 6 December 1985, p. 6.

APPENDIX E: Public Opinion on Euthanasia, Active and Passive

From "Unplug the tubes is an act of humanity": the majority of Italians and Germans are Convinced, Messaggero, Sunday 15 September 1985

(a half page on Euthanasia, complete with The Karen Ann Quinlan photo and the major article on the imminent bill in the Netherlands.)

Translation only of passages marked in pink.

The good death (literally "sweet" death). Every culture, since forever, has debated this problem which poses questions for the conscience. (Then goes on to give examples of the Cuma in Panama, who kill their sick with poison, the old and sick Polynesians who are strangled, etc., and the Greek meaning of the work "euthanasia" -- quick and easy death , the meaning of mercy death being a distortion. Professor Barni, president of the Italian Society of Legal medicine, elsewhere cited in this report, comments: " It's true, the laws of all countries and the medical associations condemn euthanasia as contrary to the principles of the medical profession, but the uncertainty of the legal and medical limits of treatment of the terminal patient remains unsettling for the medical profession and for society."

A Disturbance for the society. It is illustrated by the debate underway all of the world on two aspects of euthanasia -- the passive which consists in interrupting medical care destined only to artificially prolong a life (illustrated by the example of a sick person who lives only because attached to an automatic respirator) and "active" which prevents the administration of particilar medicine so as to accelerate the death of the incurably sick.

All over the world initiatives have been taken for a regulation of the "morte dolce" but have not arrived at an obligatory arrangement. The debate is in the phase in which it is concentrated mostly on passive euthanasia which finds public opinion ever more favorable, however with many reservations and cautions. It is illustrated by two polls, one in Italy and one in the German Federal Republic.

According to the poll of a research firm in Trieste (SWG), 7 Italians in 10 are apposed to the therapeutic continuation, that is are not in agreement with the doctor who continues to provide care for the sick even when there is no longer any hope. In practice, 7 Italians in 10 say yes to passive euthanazia, left to individual conscience. Six Italians in ten, in contrast, are opposed to active euthanasia, that is to give death to the sick one who asks for it....

All over the world initiatives to reach a regulation are being undertaken. In the USA and the Netherlands in particular. It is also being talked about in ITaly where the socialist Loris Fortuna presented a proposed law on passive euthanasia. "Good death doesn'T mean good homicide," Fortuna said, "no one wants to authorize killing, I only want to have forbidden the prolongation and persistence of therapy (extension of therapy). With my proposal I want to defend the dignity of every poor human in the terminal phase.

For the Catholic Church euthanasia is and remains unacceptable. Giovanni Paolo II, speaking to representatives of the Italian Society of Anesthesiologists, invited the doctors not to render themselves accomplices with those who practice "la morte dolce." The Church admits, however, that it is not necessary to maintain artificiallly alive a body which, by natural causes, is destined to be extinguished regardless of any care.

APPENDIX F: Processed for Maltreatment

Doctor Condemned for Having Denied Authorization of Cesarean Section

Como: a "primario" (chief of service in a hospital) in gynecology and obstetrics was condemned for having denied authorization for a Cesarean section. After five hours of discussion, the judges of the court of Como yesterday afteroon condemned to one year in prison the primario of gynecology of the hospital Saint Anna, professor Gino Grassi.

The primario was accused of punishable homicide for the death of a neonate, Massimo Tagliabue. Professor Grassi, in fact, had denied authorization for the Cesarean section and the little one suffered severe lesions to the brain during the delivery.

Condannato medico per aver negato l'autorizzazione al taglio cesareo

COMO — Un primario di ginecologia e ostetricia è stato condannato per avere negato l'autorizzazione al taglio cesareo. Dopo cinque ore di camera di consiglio, i giudici del tribunale di Como ieri pomeriggio hanno condannato ad un anno di reclusione il primario di ginecologia dell'ospedale Sant'Anna, il professore Gino Grassi.

Il primario era stato accusato di omicidio colposo per la morte di un neonato, Massimo Tagliabue. Il professor Grassi, infatti, aveva negato l'autorizzazione al taglio cesareo e il piccolo subì gravissime lesioni al cervello durante il parto.

Repubblica
Sat. 12 Oct 85

«So che sei molto coraggioso»

Lettera di Reagan a un bimbo colpito da Aids

LOS ANGELES – Il presidente americano Ronald Reagan ha inviato un messaggio personale a un bambino californiano di tre anni afflitto da Aids. Nato da genitori tossicodipendenti, il piccolo Michael, questo il nome del giovanissimo paziente, fin dalla nascita risultato ammalato di Aids, e ha trascorso gran parte della sua breve vita nelle camere degli ospedali.

«So che sei un bambino molto coraggioso – gli ha scritto il capo della Casa Bianca – tutte le persone che ti hanno conosciuto e curato sono rimaste sbalordite dalla tua forza d'animo e dal tuo carattere gioviale sempre di buon umore». Più volte, durante il suo ricovero il bambino aveva espresso il desiderio di scambiare qualche parola con il presidente, non pr parlare di sé, ma piuttosto per chiedere al capo della Casa Bianca perché tanti bambini africani della sua età morivano di fame.

Proprio in relazione alle preoccupazioni del piccolo Michael sui bambini africani, Reagan, nel suo messaggio, ha inoltre aggiunto di «apprezzare che un bambino sia così altruista e generoso» e lo ha rassicurato personalmente che la Casa Bianca sta facendo di tutto per aiutare i suoi piccoli coetani africani».

● LONDRA – Un magistrato britannico ha ingiunto a un giovane malato di Aids di non uscire dall'ospedale dove è ricoverato per timore che possa essere pericoloso per se e per gli altri. E' avvenuto a Manchester. Il nome dell'ammalato non viene rivelato e si sa soltanto che ha 29 anni. Un ufficiale sanitario della città, Anna Elisabeth Jones, si era rivolto alla magistratura dopo che il paziente aveva manifestato l'intenzione di lasciare l'ospedale malgrado il parere contrario dei medici. Il magistrato ha ritenuto che il pericolo rappresentato dall'Aids sia sufficiente per ordinare che il ricovero continui anche contro la volontà del paziente.

● PARIGI – Un bambino di 18 mesi che era stato sottoposto a trasfusioni di sangue alla nascita, avvenuta prematuramente, è morto di Aids domenica scorsa a Montpellier. La notizia è stata data da un pediatra della città il quale ha precisato che il bambino, che era in cura all'ospedale Necker di Parigi, si era aggravato nel mese di agosto mentre era in vacanza nell'Herault ed era stato rioverato in ospedale per setticemia.

Le trasfusioni cui fu sottoposto alla nascita, ha aggiunto il pediatra, furono effettuate prima che entrassero in vigore i test obbligatori di individuazione del virus dell'Aids per i donatori di sangue. Si tratta del quarto bambino morto in Francia per la sindrome da immunodeficienza acquisita.

● LONDRA – Un ragazzo che ha contratto il virus dell'Aids potrà continuare a frequentare la scuola elementare in Gran Bretagna. Lo ha deciso il suo preside, nonostante l'allarme delle famiglie dei compagni. Il ragazzo ha iniziato da pochi giorni la quarta elementare a Chandlers Ford, nella regione dello Hampshire. Soffre di emofilia e nel suo sangue sono stati trovati gli anticorpi che rivelano l'esistenza dell'Aids. I sintomi della malattia non si sono manifestati finora, ma il periodo di incubazione è molto lungo.

Duecento capifamiglia allarmati si sono riuniti nella scuola per discutere del caso. Il preside, Nigel Moore, ha detto loro che sono state prese «adeguate precauzioni», compresa l'assunzione di una assistente sanitaria. Ha aggiunto che i rischi di contagio per gli altri allievi sono minimi, e il ragazzo malato continuerà a frequentare le lezioni come gli altri.

Karen Ann Quinlan la giovane americana la cui malattia ha alimentato un lungo dibattito sulla eutanasia

Eutanasia

In Olanda anche la Dc è d'accordo Il Parlamento presto deciderà

Il diritto a una

di DIEDERIK BANGERT

L'AJA – L'eutanasia, la morte serena e indolore diventerà legale tra non molto in Olanda, se eseguita da un medico. Non solo, anche chi assisterà una persona a «liberarsi dalla vita» non sarà più accusato di omicidio. Entro il primo ottobre, il governo dell'Aja dovrebbe presentare un progetto di legge in questo senso.

Tutto questo è la conseguenza della pubblicazione – il 19 agosto scorso dopo tre anni di lavoro – del rapporto finale della Commissione Statale Eutanasia, che ha suscitato un enorme interesse in tutti i settori della società olandese, sorprendendo gli stessi sostenitori della morte serena. «Siamo stati sorpassati dagli avvenimenti – sospira Wijnand Dewitte, un gerontologo bonario – le cose stanno andando più veloci del previsto. Già adesso, Governo e Parlamento vengono vivamente sollecitati da più parti, soprattutto dagli ambienti medici, ad accelerare la depenalizzazione dell'eutanasia». In un sondaggio del quotidiano olandese *Algemeen Dagblad*, l'89 per cento degli intervistati si sono dichiarati favorevoli a tale legge. I pareri della Commissione Statale erano distribuiti secondo le stesse proporzioni: solo due membri su quindici si sono schierati contro la legalizzazione della morte tranquilla.

Si tratta del filosofo W. Klija e del docente di diritto penale W. Nieboer: «E' un atto contrario al diritto fondamentale della protezione della vita consacrato dall'articolo 2 della Convenzione europea per la protezione dei diritti dell'uomo e delle libertà fondamentali – sostengono i due professori. – Depenalizzando l'eutanasia, l'Olanda si isolerebbe e susciterebbe stupore negli ambienti internazionali». Prima di adottare la nuova legge, il Parlamento dell'Aja dovrà quindi verificare se la legge rispecchi l'articolo 2 della Convenzione, che lascia comunque molto spazio ai legislatori nazionali in materia di protezione della vita.

Dal canto suo, la Commissione Eutanasia dà indicazioni precise su quali debbano essere i termini della nuova legge. «Il rapporto – spiega il dottor Dewitte – precisa che numerosi casi di "arresto attivo o passivo della vita" (l'arresto attivo è la conseguenza dell'intervento di un medico, ad esempio un'iniezione; interruzione passiva, invece, è la conseguenza della sospensione di un trattamento, ad esempio lo spegnimento di un polmone artificiale) non sono da considerarsi come eutanasia, ma come "atti prettamente medici" che, in quanto tali, non entrano nell'ambito del Diritto Penale. Si tratta di quei casi dove un medico decide di non iniziare o di interrompere un trattamento perché il paziente lo ha chiesto o perché le cure dal punto di vista medico risultano inutili, cioè quando non hanno più alcun effetto».

Per ottenere l'interruzione della propria vita, soltanto la richiesta orale e ripetuta del paziente avrà valore giuridico. Una dichiarazione scritta sarà considerata

40

«Staccare la spina è un atto di umanità»: la maggioranza di italiani e tedeschi ne è convinta

di LUCIANO RADINO

La morte dolce. Ogni cultura, da sempre, dibatte questo problema che pone interrogativi alle coscienze. Presso gli indios Cuna del Panamá, quando un malato non ha più speranze è ucciso con un veleno tratto da una pianta. In Polinesia i vecchi Figiani, malati, sono strangolati e seppelliti vivi. Il significato che i greci davano al termine eutanasia è quello di morte rapida e facile al che il significato di decesso pietoso se è il trovimmento. Dice il prof. Bertoi, presidente della Società italiana di medicina legale: «E' vero: le leggi di tutti i Paesi e le associazioni mediche condannano l'eutanasia come contraria ai principi della professione medica ma l'incertezza sui limiti legali e morali del trattamento del paziente terminale resta di detrimento e di turbamento per la professione medica e per la società».

Un turbamento per la società. Lo dimostra il dibattito in corso in tutto il mondo sui due aspetti della eutanasia: «passiva» che consiste nell'interrompere le cure mediche destinate solo a prolungare una vita artificiale (è l'esempio di un malato che vive solo perché «attaccato» ad un respiratore automatico) e «attiva» che prevede la somministrazione di particolari farmaci in grado di accelerare il decesso del malato inguaribile.

In tutto il mondo sono state prese iniziative per una regolamentazione della «morte dolce» ma non si è mai arrivati ad una disposizione obbligatoria. Sì è alla fine del dibattito incentrato soprattutto sull'eutanasia passiva che trova l'opinione pubblica sempre più favorevole pur con molte riserve e cautele. Lo dimostrano due sondaggi, uno in Italia e uno nella Germania Federale.

Secondo un'indagine demoscopica dei Servizi integrati di ricerca (Swg) di Trieste sette italiani su dieci sono contrari all'accanimento terapeutico e cioè non sono d'accordo con il medico che continua a prestare cure al malato anche quando non ci sono più speranze. In pratica, sette italiani su dieci dicono sì all'eutanasia passiva lasciata alla coscienza individuale. Sei italiani su dieci invece sono contrari all'eutanasia attiva cioè dare la morte al malato che lo chiede.

L'indagine dell'Institut fur Demoskopie Allensbanch nella Germania Federale verteva su una domanda: va punito o no un medico che, accertate le condizioni disperate di un paziente che ha preso una forte dose di sonnifero perché inguaribile, lo ha lasciato morire? Su cento tedeschi 73 hanno risposto che «il medico non va punito», 10 che il «misfatto» merita una punizione mentre 17 non si sono pronunciati.

In tutto il mondo iniziative per giungere ad una regolamentazione, si diceva. Negli Usa e in Olanda in modo particolare. Se ne parla anche in Italia dove è stato presentato dal socialista Loris Fortuna un progetto di legge sull'eutanasia passiva, «buona morte non significa buon omicidio» – ha detto Fortuna al momento dell'illustrazione della iniziativa parlamentare – «nessuno vuole autorizzare ad ammazzare, voglio solo che sia vietato l'accanimento e l'ostinazione terapeutici. Con la mia proposta voglio difendere la dignità di ogni povero essere umano se deve terminare».

Per la Chiesa cattolica l'eutanasia è e resta inaccettabile. Giovanni Paolo II, parlando a rappresentanti della Società italiana di anestesiologia, ha invitato i medici a non rendersi «consenzienti con coloro che praticano la «morte dolce». La Chiesa ammette però che non si insista a mantenere artificialmente in vita un corpo che, per via naturale, è destinato a spegnersi al di là di ogni cura.

morte serena

valida soltanto qualora il paziente non sia più in grado di parlare; tale documento potrà essere annullato in qualsiasi momento. A questo punto la morte serena sarà depenalizzata, ma solo se effettuata da un medico, ed a condizioni ben precise. E chi assisterà una persona a «liberarsi della vita» senza essere un medico, benché sempre perseguibile, non avrà più accusato di assassinio, omicidio o uccisione su richiesta, con pene massime di rispettivamente 20, 15 e 12 anni di reclusione, come succede oggi. Sarà possibile di pene meno severe: fino a un massimo di 6 anni di prigione nei casi in cui il paziente non sarà in grado di esprimere il suo desiderio di morire, di 4 anni quando il paziente lo avrà chiesto esplicitamente. L'introduzione di sanzioni più clementi sta a dimostrare che secondo il legislatore in questi casi sono in gioco motivazioni diverse dell'omicidio.

«Come medico – racconta Dewitte – effettuando un arresto attivo o passivo della vita non correrò invece nessun rischio, a condizione che io rispetti accuratamente le seguenti disposizioni. Dovrò accertarmi che il mio paziente sia stato informato bene e che abbia preso la sua decisione in piena libertà e conoscenza di causa. Inoltre dovrò essere sicuro che non esista nessuna altra soluzione, cioè che il paziente soffra di un male incurabile».

«La formulazione di queste disposizioni – prosegue Dewitte – è l'oggetto dell'unico dissaccordo in seno alla maggioranza della Commissione. Nove membri sono del parere che il paziente debba "trovarsi in una situazione senza speranza", mentre gli altri quattro vorrebbero aggiungere "ed il suo decesso deve essere imminente e ineluttabile". Infine, dovrò consultarmi con alcuni colleghi prima di passare all'atto; il Ministero della Sanità dovrebbe stabilire una lista di specialisti ai quali dovrei potermi rivolgere».

«Dopo il decesso del paziente – spiega Dewitte – io stesso dovrò segnalare alle autorità giudiziarie che ho ottemperato ad una richiesta di morte indolore, specificando in che modo ho proceduto. La Commissione Eutanasia sottolinea anche che il medico che per obiezione di coscienza non desidera collaborare all'interruzione di una vita è libero di rifiutare ma è tenuto ad aiutare il paziente a trovare un collega non obiettore».

Entro il primo ottobre, il Governo a maggioranza democristiana, sulla base del lavoro della commissione dovrebbe formulare un progetto di legge. Il partito liberale VVD, minoritario nella coalizione, ha già avvertito che presenterà una proposta di legge insieme ai partiti progressisti dell'opposizione, PvdA e D'66, favorevoli alla morte serena, se il governo si tirerà indietro. Comunque vada, non sarà difficile in Parlamento trovare il consenso sufficiente per adottare la nuova disposizione, dato che anche numerosi membri del partito democristiano CDA sostengono le conclusioni della Commissione Eutanasia.

L'Istituto Pasteur di Parigi denuncia gli Usa

PARIGI – L'Istituto Pasteur di Parigi «sta preparando un'azione giudiziaria contro il governo degli Stati Uniti a proposito del brevetto sulle applicazioni collegate alla scoperta del virus dell'Aids (in particolare i procedimenti di diagnosi) che i francesi vanno chiedendo, senza risultato sin dal dicembre 1983.

L'ha detto a «Le Monde» il direttore dell'Istituto Pasteur, professor Raymond Dadoner, dopo aver ricevuto al riguardo dal ministero americano della Sanità una risposta che ha definito «sostanzialmente negativa».

● WASHINGTON – Un appello al presidente Ronald Reagan perché intervenga a calmare le acque per quanto riguarda il problema dell'Aids è stato lanciato da Victor Bender, colpito della malattia ed oggi volontario di un centro di aiuto sanitario per omosessuali, in un intervento davanti ad uno speciale sottocomitato del Congresso. Il sottocomitato sta esaminando quale deve essere la risposta del governo al continuo avanzare dell'Aids negli Stati Uniti. La questione sta diventando ogni giorno più preoccupante nel Paese.

APPENDIX G:

Notes from "The Patient's Bill of Rights", Corriere della Sera, Thursday 3 October 1985

How patients and their families are rebelling against the "hospital power." Liguria Region approved its new law which protects them; regions of Veneto, Peimonte, Publia, Abruzzo, CAmpania guarantee the continual presence of parents next to their babies; But, notwithstanding this positive facts, the situation remains difficult and the statements of principle too often remain just words.

Someone has counted how many are the rights of the patient, in hospital and out. They are, in the present historical moment, 30 or 40. More or less...I have before me the Bill of Rights of the Patient in Liguria, passed 26 April 1985...There are many regions that have similar laws or in which they're in advanced state of discussion -- naturally we're talking about Tuscany (Florence the capital), Piemonte (Torino), Emilglia Romana (communist-controlled Bologna) -- all in the north.

The Elderly: In common in these laws is that they guarantee the presence of the parents next to sick children. Specific rights are spelled out for three other categories: women, elderly, and chronically ill. To be a woman, in a hospital, is in fact a permanent condition like a chronic sickness and of weakness like that of the elderly.

Where there are no regional laws, Patients' Bills of Rights are solemnly proclaimed, from the grassroots initiative; there are 30 such, many of them autonomously signed by the local authorities, such as in Lecce, Varese, ...Rome...

We're talking about "Bills," laws and non-laws that are founded on the tough experience in wards and clinics, matured in the long lines in front of the USL (health union) window, waiting for the documents on principles of the most diverse international organizations, distilled by 60,000 letters which in the 5 years since its founding (in Rome 1980) the Court for the Defence of the Rights of the Patient has received, which in turn is part of the Federal Democratic Movement. (MFD), which was ounded by the sociologist Quaranta,.Caroleo, present secretary general, and Giovanni Moro, son of the president of the Christian Democrats killed by the Red Brigates. Today the "Tribunal" (which isnot a tribunal (although myths and rites please people, says Quaranta) are informal organisms for denouncing, are not concerned with following an isolated case as in transforming it into a case study, and example, "political" that is, thus into material for one of the Bills for the Patient, which may come together. The Movement believes that less and less, fearing a dangerous crystalization into a single national Bill, for which, in truth, a government commission in the ministry of Health has already been constituted.

/some history of the International Bill of Geneva in 1948. World Health Organization's Rules for the regulation of clinical experimentation on humans. 1972 Bill for Patients by the AMA. __/ In 1976 the Council of Europe got moving and proclaimed the "Recommendation number 779 for the Protection of the Rights of the Sick and the Dying." A European Bill of Rights of the Sick was solemenly passed by the European Parliament at Strasburg 19 January 1984 after which the European COmmission of Private Hospitalization came out with its own Bill for the REspect of the Human Person in Hospital.

9) If you see cockroaches, take them for hallucinations. In fact, they go away.

10) Comfort the moribund who invariably is placed in the bed next to yours.

11) Even if you are convalescing, keep your pyjamas on (if not, how would the nurse who pases know to give you orders?). It is also prohibted to leave the hospital for a brief Sunday vacation; you'll lose you bed place.

12) Get used to undressing in public, to usin toilets on stilts, and to doors that don't exist.

13) Prepare yourself for the violent noises and the sudden, unjustified putting on of lights" (paraphrase from the "Bill" from the Umbria region, 1981). Luciano Girotto of the Russell Group for the Defense of the Citizen (who has an advisor in the city government) "My wife died of a brutal illness, screaming because of the atrocious pain, while under her windows the cars of the visitors were trumpeting and the motors of the nurses who were going off duty thundered ferociously."

14) Don't even try to ring the call bell, the night light, the visit light, or to set up the screen. (from the "Bill", Lazio -- Rome, 1983)

15) Accept the distinction of gender, renouncing any respect as a woman (Council of Europe Recommendation 1984).

16) But above all recounce the right to information. It is the most serious and common cause of discomfont for he who has to furnish it to you. From the information about why you are here, to when you will leave, of what they have administered to you, of the plan of the hospital. Keep quiet, better to know nothing. But this subject, for its importance, merits a discussion by itself.

Before closing, however, this section of our investigation, we must remember that even in this field there are noble exceptions, to whom go all our rispect. The respect that is always due to the minority.

FA[illegible]OMMENTI

[illegible] dove [illegible] la speranza di guarire [illegible]

La carta dei diritti del malato

Come i degenti e le loro famiglie si ribellano al «potere ospedaliero» - La Regione Liguria ha approvato una sua legge di tutela che protegge gli ospiti delle corsie - Veneto, Piemonte, Puglia, Abruzzo, Campania garantiscono la presenza continua dei genitori accanto ai loro bambini - Ma, nonostante questi fatti positivi, la situazione rimane difficile e le petizioni di principio troppo spesso restano parole

[illegible] quanti sono i diritti del [illegible] in ospedale o Asmi. Sono, nel momento in cui scrivo, 20 '47 ma, Una più, una meno. Altrettante «carte» [illegible] tante? Come leggi di almeno il cittadino che si accosta al servizio sanitario, di spesso [illegible] stratto. Ho qui davanti a me la Carta del malato della Regione Liguria. E' una formale legge regionale, Legge 26 aprile 1985, n. 27, pubblicata sul bollettino ufficiale n. 20 del 15 maggio 1985. Si intitola «Tutela dei diritti della persona che usufruisce delle strutture sanitarie». Sono numerosi le Regioni che si sono fornite di leggi analoghe o le hanno in stato di avanzata discussione: naturalmente si tratta delle solite regioni Toscana, Piemonte, Emilia-Romagna. Insieme a queste, altre regioni (Veneto, Piemonte, Puglia, Abruzzo, Campania) hanno dato in precedenza a leggi sul trattamento del bambino in ospedale.

Gli anziani

Una norma comune a queste leggi è quella che garantisce la presenza continua dei genitori in corsia accanto al bambino malato. Seguono altri diritti specifici che vedremo più avanti. Diritti specifici sono enucleati per altre tre categorie: donne, anziani ed ammalati cronici. Essere donna, in ospedale, è infatti una condizione permanente come la malattia cronica o di fragilità come quella degli anziani.

Dove non esistono leggi regionali, vengono solennemente proclamate «Carte dei diritti del malato». Si inizia[illegible] popolare (se ne contano già 30) molte delle quali stabilmente sottoscritte dalle autorità locali, come a Lecce, Varese, Sassari, Cagliari, Roma, Pistoia.

Si tratta di «Carte», leggi e non leggi che siano, [illegible] sulle dure corsie[illegible] di corsia e di ambulatorio, inalberate nelle lunghe file davanti agli sportelli delle USL, ispirate ai non pochi solenni documenti di principio dei più diversi consessi internazionali, distillate dalle 60 mila lettere che in cinque anni dalla sua fondazione (Roma, 1980) ha ricevuto il movimento dei «Tribunali per la difesa dei diritti del malato», che si rifà a una volta al Movimento Federativo Democratico, l'MFD.

L'MFD è stato fondato dal sociologo Giovanni Querenta da Francesco Cavicchi, attuale segretario generale, e da Giovanni Miceli, figlio del presidente della DC ucciso dalle Brigate rosse. Oggi i «Tribunali», che tribunali non sono («ma alla gente piacciono i nomi altisonanti», dice Giovanni Querenta), ma degli organismi informali di denuncia non si preoccupano tanto di perseguire il caso isolato quanto di trasformarlo in caso emblematico, «politico» appunto, da trasformare a suo volta in materia per una delle tante «Carte del malato» che dovrebbero condurre poi (ma il Movimento si crede sempre meno, temendo una particolare cristallizzazione) in una Carta del malato nazionale, per la quale, in verità, [illegible] già [illegible] una apposita commissione presso il ministero della Sanità.

I diritti del malato affiorano per la prima volta come oggetto di un documento pubblico e solenne nella Carta Internazionale di Ginevra del 1948 e vengono implicitamente ricepiti dalla Dichiarazione Universale dei Diritti dell'Uomo, che, con l'astensione del blocco sovietico, del Sudafrica e della Arabia Saudita, sarebbe stata da lì a poco (10 dicembre) solennemente enunciata dall'Assemblea Generale delle Nazioni Unite.

L'Organizzazione Mondiale della Sanità (OMS) aveva già, da parte sua, presentato le «Norme per la disciplina delle sperimentazioni cliniche sull'Uomo». Nel 1972 una [illegible] Carta del malato venne proclamata dalla Associazione Medica Americana. Nel 1976 si aggiunge il Consiglio d'Europa che [illegible] la «Raccomandazione n. 779 per la Tutela dei Diritti dei Malati e dei Morenti». Una «Carta europea dei Diritti del Malato» è [illegible] nata [illegible] dal Parlamento Europeo a Strasburgo, 8-10 maggio del 1979; [illegible] la Commissione Europea sulla Condizione Umana in Provaia si era già data, a Le Havre (1978), una sua «Carta per il Rispetto della Persona Umana in Ospedale».

Queste stratificazioni, intersezioni, quasi successive serie di dichiarazioni di principio non sempre stata ovviamente necessaria, è elementare, se gli stessi principi non fossero stati con la stessa straripante, interrotta e quasi ossessiva frequenza e profondità, [illegible] palesemente violati.

Ora, poiché sarebbe troppo ovvio e noioso elencare i [illegible] 30-40 diritti del malato, ci permetteremo, con un minimo di perdita, semplicemente riballandoli, di tracciare quella che potrebbe essere l'«Anatomia dei Diritti del Malato», ovvero la «Carta dei Doveri» delle Convenzioni del Malato in Italia onde assicurare finalmente serenità e benessere al Personale Sanitario».

Si raccomanda, dunque, ai Signori Malati e Candidati tali:

1) Essendo impedita la libera scelta dell'ospedale e del medico destinato ad operarvi, astenetevi dal aggravarvi onde obbligare l'Ufficio accettazione dell'ospedale da voi preferito ad ricoverarvi -per motivi di urgenza- (sulle prenotazioni ospedaliere ha aperto una inchiesta la Pretura di Firenze).

2) Arrivate in ospedale con coperte da campo e maglioni di lana, per l'ipotesi non infrequente di dovere parcheggiare intere mattinate all'incrocio delle correnti d'aria nei corridoi dell'astanteria. Lenzuola e federe sono di rigore negli ospedali del Centro Sud, ma [illegible] [illegible] apprestate anche in qualche zacca debole del sistema Nord-lombardo.

3) Prima di entrare in ospedale fatevi consigliare dal medico di fiducia pastiche antiasfitico, orale (di facile deglutizione), essendo improbabile che abbiate un bicchiere di acqua, pulito sul comodino, se c'è un comodino).

4) Preparatevi al trattamento meno rapido possibile (dice il professor Candia, sovrintendente del Policlinico Gemelli di Roma: «I medici tendono a trattenere il malato già in cura, per evitare che ne debbano prendere in carico uno nuovo, con nuovi problemi» (meglio vivere con una «rendita di posizione», in questo caso le «vostre» posizioni, ortopediche).

5) Rinunciate alle vostre privacy, alla vostra vita privata e, se potete, alla vostra personalità. Qui non siete né capofilo né preside di scuola secondaria superiore né professore d'orchestra della Scala o, praticamente, nemmeno cittadino della Repubblica. Accettate il «tu» dell'infermiere senza discussione, che ricambierete con un «lei» esclusivo e servile «alla Fantozzi». Siete già fortunati. Ad altri capita di essere chiamati con un «Vieni qui, ulcera perforata!» o «Come stai, bronchiectocronico?». In un altro ospedale saresti solo un numero, un numero di letto: «Alzati un po' su, quattrocentoventidue!» (il lettore sano penserà che io stia facendo del guerrachismo di cattiva lega: chi è stato «423» o «ulcera perforata» se quanto siano serie le mie «battute»).

6) Se siete agnostico, preparatevi a recitare preghiere mattine e sera (preghiere cattoliche, si intende) e, comunque, a sfantare i passi della vostra convalescenza appoggiandovi ad altarini della Madonna, sia detto con riverenza, disseminati in misura di almeno tre per corridoio.

7) Rinunciate a conoscere per nome il personale medico, paramedico e ausiliario. Solo gli ospedali più civili prescrivono cartellini differenziati anche per categoria. Non parliamo di divise. Un primario un po' [illegible] vale un portantino (portatore di barelle) un po' curato.

8) Rinunciate ai vostri normali (si normali di tutti) orari di veglia (qui dalle cinque alle sei), di pasto (qui alle 11.30 e alle 17.30-18, con la prospettiva di 13 ore di digiuno fino all'indomani). Non trascurate il peso durante le visite: lo portano via.

9) Se vedete scarafaggi [illegible], per allucinazioni. Infatti possono.

10) Consolate il moribondo che immancabilmente vi è stato collocato nel letto accanto ad consumento (Inchiesta Tribunale del Malato, Ministero della Sanità).

11) Anche se siete convalescente, mantenetevi in pigiama (se no, come farebbe l'infermiere di passaggio a darvi [illegible] dini?): E' proibito anche [illegible] sciare l'ospedale per una breve vacanza domenicale, partendo il posto-letto.

12) Allenatevi a spogliarvi in pubblico, a servirvi dei gabinetti igienici su [illegible] porte inesistenti.

13) Preparatevi al «calcio vicendi» o alle assenze[illegible] previste e ingiustificate dell'ace- [illegible] dalla «Carta della assistenza sanitaria» del Tribunale del Malato, giugno 1981 Denuncia il signor Luciano Ch[illegible] retto di Treviso, presidente del «Gruppo Russel per la difesa del cittadino» (che ha un suo [illegible] nigliere in Comunale): «Mia mo[illegible] gie morì di un brutto male gridando per i dolori atroci mentre sotto le sue finestre stranamente vano le note dei [illegible] stieri e rombavano forsi [illegible] moto degli infermieri che finivano il turno...».

Il disagio

14) Non pretendete (si tratta di diritti del malato previsti nella proposta di legge repubblicana Matteoni e Bernardi del 24 settembre 1983 alla Regione Lazio) di disporre di «campanello di chiamata, di luce notturna e luce-visite, di un paravento».

15) Accettate la distinzione di sesso, rinunciando al rispetto come donna di cui alla Raccomandazione del Consiglio d'Europa del 2 febbraio 1984.

16) Ma soprattutto rinunciate al diritto all'informazione. E' il motivo più grave e frequente di disagio per chi deve fornirvela. Dall'informazione su perché siete qui, dal quando ve ne andrete, di che cosa vi somministrano, della pianta dell'ospedale. Tuttavia, «tanto non capite niente». Ma questo argomento merita, per la sua gravità, un discorso a parte.

Prima di chiudere, però, questa puntata della nostra inchiesta dobbiamo ricordare che anche in questo campo esistono nobilissime eccezioni, alle quali va tutto il nostro rispetto. Il rispetto che è dovuto da sempre alle minoranze.

Nicola D'Amico

(continua - 2)

I malati parcheggiati nel corridoio dell'ospedale Maggiore a Milano

LIFE SUSTAINING TECHNOLOGIES: ELDERLY IN JAPAN

Rihito Kimura

In this report I shall analyze the issues which life sustaining technologies have created with respect to the growing number of elderly in Japan. As the Japanese situation is quite unique, a general overview is needed in order to appreciate the specific technical issues which relate to the penultimate stage of life. Finally, I shall deal with future trends in the care of the elderly in the Japanese health care system, as Japanese health care policy is now at a critical turning point where radical changes can be expected in the near future.

I. Background: The Elderly in Japan

A. The Uniqueness of the Aged Japanese Population

Japan is a small country. Its total territory is almost the same size as the state of California, but only 21% of this area is inhabitable. The total population is about 118 million, which is just over half of the U.S. population (1982). The Japanese population is only 2.5% of the total world population and Japan's land space occupies only 0.28% of the world. Also noteworthy is the fact that Japan's economic activity is so high that it is consuming 10 times more energy than the U.S. [1] In this setting, Japan's elderly population

is growing rapidly, even when compared with other industrially developed nations (Chart I)

The birth rate in Japan has been slightly decreasing since the 1920s. Since the end of World War II, both birth and death rates have been rapidly decreasing. In 1955, the elderly (over 65 years old) composed 5.3% of the total Japanese population; 7.1% in 1970; 10.1% in 1985 (see Table I). The second unique fact about Japan's elderly population is the high number of persons who live with one of their married children, usually the eldest son. Even though this traditional life style is changing rapidly, many households contain three generations, particularly in rural areas (see Chart II). Thirdly, because the "aging process" and "old age" are to be respected, Japan celebrates a unique national holiday every September 15th -- "Respect-for-the-Elderly Day." This began in 1966. "Respect-for-the-Elderly Day" (Keiro-no-Hi in Japanese) came about according to some cynical critics due to the lack of such an attitude in Japan's rapidly-changing society. [2] However, the Japanese believe respect remains of prime value even among the young generations as is reflected in their language and social behavior as members in three-generation families.

Because of the vitality of these kinds of social values, the elderly themselves view their future happily as one in a peaceful family setting, playing with the grandchildren and ending their lives surrounded by their offspring within their

home-setting and in their own community. However, a trend toward an independent life style (rather than security within family dependency), lack of housing in urban areas in order to accomodate elderly parents, economic motivation for the elderly to continue to work as long as possible (even after retirement), and rapidly changing social values that erode the traditional life style all cause hardship on the aged.

B. Health of the Elderly in Japan

In 1891, the average longevity of the Japanese male was 42.8 years, and 44.3 years for the female. In the 1950s, the longevity for both sexes rose to 60 years and above. In 1984, life expectancy for women was 80.18 years, and 74.54 for males.[3] Today, Japan has the highest average life expectancy in the world. Extended average life expectancy, very low infant mortality rate, a decrease in deaths caused by infection, a higher living standard, and the establishment of various public health programs throughout Japan, have made an enormous contribution to the health of the aged Japanese. However, so-called "geriatric diseases" have increased very significantly -- from 46% in 1960 to 63% in 1983. Both Great Britain and the U.S. have also experienced an increase in "geriatric diseases" (the most important of these are cardiac disease, high blood pressure, cerebral apoplexy, and cancer), and the death rate has increased very gradually in 60% and over. For many years, in Japan, cerebral apoplexy has been the

number one cause of death for the aged, but this has been decreasing since 1970; today cancer has become the major cause of death, followed by apoplexy. (The death rate from cancer is 148.3 per 100 thousand; the death rate from apoplexy is 122.8 per 100 thousand.)

Before 1960, the Japanese elderly usually died at home. In Japan, a census questionnaire included items relating to the place of death; according to this survey, in 1955 only 16.5% died in an institutional setting (e.g., hospitals or nursing homes). The situation has been changing rapidly, and in 1975 over 50% died in institutional settings; 63.1% in 1963. These changes are also due to the increasing accessibility of health care for the elderly, particularly since 1983 when medical and health care for the elderly became almost cost free. According to this data, the percentage of elderly who still die at home is relatively high compared with previous generations. Statistics on causes of death at home reveal the following: 1) rosui (naturally caused "senility" due to old age) = 83.9%; 2) cardiac disease = 43.0%; 3) cerebrovascular related disease = 41.6%; 4) pneumonia and bronchitis = 34.1%. [4]

It is projected that health care costs for the elderly, if recent trends continue (1978-1979), will increase enormously during the period 1980-2025 [See Table I. The growth pattern of the number of hospital patients per day (*) and that of the number of in-patients per day (+) are described by age and sex for two different years, one in 1980 and the other in 2025 (See

Charts and)]. These computorized charts indicate that the number of aged hospital patients and in-patients will increase enormously in the 21st century when the aging of the population dramatically accelerates. The greatest demand for hospital and clinic services will appear around the year 2020 (See Table 2), if present trends continue.

II. Cultural, Bioethical, and Legal Aspects of Treating the Aged

It seems that some physicians still hold onto rather traditional notions of "death criteria," as does the Japanese lay public.. According to statistical data on the issue of "brain death criteria" surveyed in 1985, the situation is changing rapidly. Physicians tend to avoid "malpractice" suits or conflicts with the family members of dying patients who accuse them of ceasing treatment before the patient's end of life. One physician regretfully mentioned his own experience of having provided long hours of explanation to family members of a dead patient who accused the attending physician of misconduct. [5]

There is now a trend to diagnose the death of patients by applying total "brain death criteria" as the accepted standard and thus to cease treatment when this condition arises. [6]

The moral, financial, and social aspects of "brain dead" patients has become a very critical problem in Japan. If the family members do not agree with the physician's judgment that

the patient is dead, all treatment, including hydration and nutritional support, will be continued. It usually takes three to five days and at the most two weeks after the physician's judgment for the family members to agree that the patient is dead on the basis of "brain criteria." [7]

In many cases almost all Japanese family members agree that aggressive and positive intervention to support the patient's life is a sacred obligation of the society. Then, faced with the reality of continuous and expensive life support of unconscious, bedridden elderly patients, many serious problems arise.

Japanese physicians educated to defend paternalistic Confucian ideology of medical morality (known as "Jin-Hyatsu") usually think of themselves as final judges in decisions to provide treatment or to withdraw or withhold it. A patient's autonomy and rights are not yet well established values as is the case in the U.S. All the information relating to patients is not necessarily given to the patients themselves, or to their families. [8] "Right of treatment" by physician is an established principle and is recognized by law; the patient's obedience is expected as part of his tacit agreement with his physician. However, there i a trend toward more open, informed, and patient-centered approaches, although change is slow in coming. [9]

So-called DNR order (do not resuscitate) are not officially accepted among medical professionals even though

there has been some agreement to employ DNR coding in each medical professional group which work in the same clinic and hospital setting. [10] Application of DNR orders differs among physicians.

A. Foregoing Treatment in Japan: The Legal Problems

There are three unique yet common phenomena among the Japanese which relate to end-stage medical treatment, particularly in the case of terminally ill patients: 1) not telling the truth because of fear of increasing the patient's despair; 2) right to treat which is strongly confirmed in legal cases; and 3) medico-technological interventions up to the last moment of a patient's death; this is expected to be provided and every effort must be made by the medical team. [11]

Though this situation is changing gradually, many people still think that the patient's obedience to his physician is mandatory. The patient's exercise of his autonomy is not possible in the Japanese medical setting; even the notion of "informed consent" has not become an well-established principle in Japanese medicine. [12]

Due to the dehumanizing process of recent medical services in Japan, and because of the lack of communication between medical staff and patients over treatment decisions and the use of medical treatment in prescribing medicine and surgical operation (not to mention increasing misconduct of some medical professionals), [13] malpractice suits are now

increasing in number, though the total number of litigations is quite small compared to the U.S. There were approximately 1400 malpractice suits in Japan by November 1984. [14] The Japanese people prefer to resolve disputes out of court since medical problems are not usually remedied by recourse to legal solutions.

The special resolution called as "Jidan"(Private settlement) is very common by the arrangement of the persons concerned together with medical professional belonging to each local medical associations. "Wakai" and "Chotei" are also possible in several cases. [15]

Actually, almost all patients in Japan are given an opportunity to sign a document at the time of admittance to the hospital usually for a surgical operation which says "no complaint whatever happens to patients themselves." [16] This is only a matter of formality, according to hospital administrators; however, many patients believe that this ha some legal binding power over patients. But appeal to this has been declared void when set forth to justify malpractice litigation and compensation. [17]

The "living will" has not been accepted among the Japanese public, even though the Japanese Euthanasia Association has been active since the 1960s, and has changed its official name -- since 1983 it is the Japanese Society for the

Right to Die with Dignity. This organization is affiliated with the World Federation of Right to Die Societies and in 1976 organized the first International Conference on Euthanasia in Tokyo, Japan.[18]

There is also a different type of association which claims the right not to be treated. The official name of this association is the "Association for the Rejection of Medical Treatment."[19] Even though a member of each organization holds membership which is recognized at the time of an accident or some emergency situation, this person presumably would be treated and this attitude is their professional calling according to the physician's ethical and legal obligation provided by law.[20]

There is no "ethical" or "critical care" committee in Japan which would provide medical services or assistance in clinical and moral "decisionmaking." Physicians are the decision makers in almost all cases, even though the patient's family members would be given some information and given an opportunity to state their opinions.[21] "Persuasive communication" from the side of the physician is quite common, especially when the case is serious. This is an expression of the traditional paternalistic approach by the physician to the patient; this attitude will in all likelihood prevail in the future.[22]

A positive attitude of Japanese physicians is found in their strong sense of commitment to their patients and family

members; this includes the patient's and family's daily life as well as in the funeral ceremony. In some cases this is an expression of professional responsibility considered in wider perspective. It should also be mentioned that the Japanese Heath and Insurance System which is controlled by the government includes the prescribing of drugs, thus the over prescription of drugs, unnecessary surgical operations, and futile efforts to prolong life regardless of the terminal situation of the patient.[23] Patients as well as patients' family members might themselves have caused these trends by placing too much emphasis on the dependency and respect for the medical professional to whom many people are reflexively obedient.

For more than 1000 years, in the Japanese culture, medical and health care was regarded as "Jinjytsu." "Jin" signals human compassion and love, and "jyutsu" is art. According to Confucian moral teaching, medical practice should be "art of Jin" (which first appeared in print in 982AD in the oldest existing Japanese Medical Encyclopedia of 30 volumes. The Japanese medical profession has integrated some key religious ideas from Shintoism -- purifying the body by washing; from Buddhism -- giving mercy to the sick and aged; and from Confucian ethical teaching -- to practice the action of love.[24]

Traditional Japanese and Chinese medicine have been well accepted as part of daily health practices: accupuncture,

moxebustin, and herb medicine are all based on a long tradition and employed to alleviate particular diseases, such as stomach pain and headaches. In the context of feudalistic Japanese society, respect for the aged as well as respect for those who have extraordinary knowledge and wisdom in the medical arts was presumed. In many cases physicians were regarded as intellectuals who were literate in the Japanese and Chinese classics and the teachings of Confucius.

However, this has been rapidly changing in recent years due to the acceptance of Western medical practice in the mid-19th century. One result has been the government initiated modernization and socialization of Japanese medical services.

There has been a strong undercurrent of traditional Japanese and Chinese medicine even during this recent process of Japanese medical modernization, particularly since the beginning of the 1970s. We today are witnessing a revival of this traditional medicine. It is also evident that Japan's elderly people have a tendency to consult traditional medical professionals for alternative healing treatments.[25] In order to practice Eastern medicine government regulations require the practitioner to have a professional license.[26]

III. Financing Health Care and the Right to Treatment

Japanese Medical and Health Care Legislation for the Elderly: 1963 to 1985

The Law for the Elderly's Welfare was promulgated in 1963. In Article 2 of this law, the fundamental aim of the legislation was stated: "The elders shall be loved and respected as those who have contributed for many years to the progress and development of society, and healthy and peaceful life shall be guaranteed." Article 3.2 says that in accordance with their desire and ability, elders shall be given opportunity to engage in appropriate work and to participate in other social activities.

In 1961, before the enactment of this law, Japan had established a system of national health and medical benefits for all of its people, regardless of the premium paid (based on income) or financial situation. The original pattern of this plan, under the name of Health Insurance Law, was promulgated in 1922, and had been enforced since 1927. In 1938, a National Health Insurance Law was enacted. Due to the unusual situation during and after the war, however, the government could not implement this law until 1961. The welfare, health, and medical insurance policy became part of the political agenda around the end of the 1950s, and was expanded during the 1960s following Japan's economic growth in world trade.[27]

In Article 25, the Japanese Constitution of 1946 specifies the following responsibility of the State: "All

people shall have the right to maintain the minimum standards of wholesome and cultural living." In all parts of life, the State shall endeavor to promote and extend social welfare, security and the public's health. Usually, this provision is regarded as state principle, and people's claim to these rights is guaranteed through the enactment of particular positive laws which relate to welfare, health, and medicine. The 1963 Law for the Elderly's Welfare was a positive law for the implementation of Article 25, as well as of Article 13, which provides that: "All of the people shall be respected as individuals. Their right to life, liberty, and the pursuit of happiness shall, to the extent that it does not interfere with the public welfare, be the supreme consideration in legislation and in other governmental affairs."

One of the most radical policies for the elderly relates to virtually cost-free medical and health care, which was officially accepted by the Japanese government in 1972, following the success of the excellent free medicine and health programs of several local governments. This was one of the most unique welfare accomplishments in recent Japanese history.[28]

In the framework of Confucian ethical principles, the medical profession monitored its strong paternalistic values even after the radical reformation of medical education from the traditional Chinese system to a modern Western one. In pre-war Japan, medical benefits and health services were not regarded as a "right" of the people.[29]

One of the earliest movements toward "free health and medical services for the elderly" occurred in the northern mountain province -- Iwate prefecture. Formerly, this region was known as a poor area, with no resident physicians in full service to provide medical and health care. In 1949, in the village of Higoroichi (Kesen-gun) an integrated policy for insurance and medical services was initiated by the mayor, Suzuki; it was expanded to 24 local governments in the prefecture by 1952. The policy was almost abolished around 1955, however.

In the same prefecture, the Sawauchi village started a regional health and medical service system, with the full cooperation of the people, physicians, the medical organization, and the Administration. This is now well known as the "Sawauchi System."[30] In 1960, for the first time in the nation, a totally free program was available for health and medical services for those over 65 and for newborns and infants. In 1961, those aged 60 or older could apply for this program.

The Sawauchi System, initiated by a local people's movement, had a powerful impact on local communities throughout Japan. By the end of the 1962, 69 local communities had established a similar system. In 1969, the Tokyo Municipal Government also decided to provide a similar service for people over 70. More significantly, the success of the Sawauchi System led directly to the government's amendment to the Law

for the Elderly's Welfare and it endorsed free health and medical care for people over 70.[31]

Until 1982, therefore, there were continuous improvements in the provision of health care for the elderly. The Japanese Constitution, the 1963 Law for the Elderly's Welfare, the amendment of 1972 that provided free medical care for the elderly, and the existence of social insurance, as well as national health system -- all were the embodiment of the people's "right to health and medical care."

Social movements in local communities, together with strong endorsements by local governments and medical service staffs, were the initial forces behind realizing these rights in the context of Japanese state policy. However, pressure arose to resist socialization of health and medical care, for financial reasons. The equal distribution of health and medical care resources became a powerful item on the political agenda in the 1980s.[32]

The Law of the Health and Medical Services for the Aged aims to improve national health and to promote the welfare of the elderly, by implementing a policy incorporating prevention, treatment, and rehabilitation for the aged. This legislation is regarded as one of the positive laws which fulfills the "right to health care and social security" of the constitution of 1946. Just as with the Law for the Elderly's Welfare, however, Article 2.2 of the new law mentions that "the people shall be given the opportunities to receive appropriate health

services in order to enhance the health of the aged." There is no positive statement about the "right" of people, including the aged, to state or local government (including local government) health and medical services. Paternalistic and bureaucratic attitudes can be traced very easily in the legislative process regarding the wording of laws relating to the welfare of the elderly.

According to Article 12 of this law, the following health services for the elderly are provided:

1. Health notebooks [25]
2. Health education
3. Health consultation
4. Health examination
5. Medical services
6. Rehabilitation therapy
7. Visits to provide home-care for patients at home, and
8. Other necessary services in accordance with particular ordinances.

These medical services are provided by the local government for those 70 or older, and for those between 65 and 70 who have designated disabilities (according to the Ministry's ordinance and after confirmation by the local authority), and are covered by medical care insurance; public and insurer contributions are used as resources. In the case of out-patient treatment, the cost-sharing is 400 yen (approximately $1.60) per month, while the in-patient elderly

have to pay 300 yen ($1.20) per day for the first two months (or for the first 50 days for insured persons). The other health services specified in this law are provided for those 40 or older and are arranged at the local level.

There are some problems related to the enforcement of this law. First, not all local governments have a "cost-sharing health and medical care policy for the aged." In 1983, there were still 26 local governments in 9 prefectures that had their "free" health and medical policy for the aged, which was contrary to policy of the central government. The sanction against these local governments took the form of cutting government support for the programs at the local level.[33]

The second problem arises with the special limit regarding the elderly's medical costs. Medical treatment and hospital-related expenses have been limited to certain lengths of stay in the hospital. These gradual stages or limits are too rigid and too unreasonable for some patients with chronic, serious conditions. [26] The amount of out-of-pocket expenses for the continuation of such medical care in the future will surely increase.[34]

The third problem: the extremely low funding allowed for visiting services to provide home-care to patients, especially the elderly. It was certainly admirable that such a fee was approved for the first time for home-care patients in the community, but again, the time limit for this service affects the quality of care. The elderly are not encouraged to

stay in hospital for long for their medical care; after they are discharged, they are not given continuous care.[35]

IV. Technological Issues Related to Geriatric Care of the Critically and Terminally Ill Elderly

Japan's medical practice reflects the values of Japanese society, and is affected by historical, moral, and religious traditions. Medical treatment is usually equally given to all the people according to the need and the urgency, regardless of age, sex, and source of payment. The entire Japanese population is protected by National or government-regulated health insurance. The elderly are shown great respect because they have contributed so much to the society during their long lives. This is one reason which explains the provision of free medical care at the local and National level, and has been supported by public funding since 1983 to those who are over 70 years of age. (The Law for the Health of Elderly, 1983) Even though the idea of cost-sharing by the elderly was introduced by amendment to this Law of 1983, the expenses accrued by the elderly are not too burdensome (according to the official statement of the Ministry of Health and Welfare, 1984).[36] There are positive incentives to Japanese physicians who receive elderly patients, and the reimbursement for medical services fees is guaranteed by the National and/or local government-controlled health and medical insurance scheme.

A. End Stage Renal Disease (ESRD)

The most recent data relating to chronic haemo dialysis treatment, published in 1984, shows an increasing number of patients in higher age groups. The average age of dialysis patients in 1983 was 51.9 for males and 52 years for females. In 1983, the oldest patient receiving dialysis treatment was 98 years old, and in addition, in the same year, 164 patients over 80 years of age began dialysis treatment.[37]

There were 48 dialysis machines in 1966 and in 1983, 24,474 machines were working (with a maximum capacity to assist 68,813 patients). In 1968, there were only 215 dialysis patients in Japan, and by in 1983 the number of patients was 53,017, about 246 times more than in 1968. In comparison to other countries, the number of dialysis patients is very high in Japan. There are 404.2 patients per million in Japan and 237.0 in the U.S.; 25.0 in Canada; 350.0 in Europe, respectively (per million population).[38]

Because it i still unexplained why so many Japanese dialysed, it may be that this technology is being used more than is necessary.

The average age of dialysis patients (as of December 1983) was 48.25 years for both sexes, and 47.85 years for males and 48.86 years for females. This data also shows that around 13% of the dialysis patients are over 65 years and around 46% of dialysis patients are over 50 years.

There are no criteria other than need in order to receive dialysis treatment in Japan. All those who need dialysis were totally compensated by one insurance scheme; they applied to all Japanese citizens until 1984. Amendments to the Health Insurance Law of 1984 require dialysis patients to pay partial costs of treatment, up to 10,000 Yen (approximately $50 U.S. dollars per month). The rest is paid by the insurance scheme to which each patient belongs.

One of the reasons for the increase in use of dialysis machines is the comparatively easy access to dialysis centers that are readily accessible in Japan's major cities. A network is also provided for prefectures (see Map of Japanese Dialysis Network). A patient finds it possible to go to a center for dialysis treatment several times a week and within short distances from his home.

Dialysis treatment is also available at home. Only 132 persons (0.2% of total dialysis patients) were dialysed at home as of December 1983. But this number of patients is now increasing given the use of the relatively new popularized method of Continuous Ambulatory Peritoneal Dialysis (CAPD). In 1985, 1400 patients were using CAPD because of the official endorsement for insurance policies by the Ministry of Welfare and Health, and 800 patients were receiving this CAPD at home. CAPD use is much more convenient for many patients due to the simplified method of dialysis, less cost, and flexible application according to the working and life styles of individual patients.[39]

Because of this national insurance incentive, even though medical treatment fee by point for this CAPD is not enough according to some critics (consultation and advising fee for CAPD patients at home was decided at 1500 fee points limited twice a month only. Total amount per month would be around U.S. 160 dollars), this CAPD would be used more and more in Japan. There are now 120 institutions throughout Japan which offer CAPD. Patients affiliate according to the (Feb. 1984) notice issued by the Director of Medical Service Section of the Ministry of Welfare and Health.

Under the present scheme of health insurance, Japanese men and women, young and old, utilize opportunities for the treatment by dialysis at various regional centers. A very recent policy to provide home treatment of dialysis is the result of a policy shift from financially expensive hospital care to moderately inexpensive home care. However, in order to make home care more available to those who prefer to stay at home rather than remain in hospital, elderly patients need an effective support system which must include the establishment of a "visiting nurse" network; this began only recently with the endorsement of the Ministry of Health and Welfare. It applies to those patients who are under the care of medical institutions but who stay at home. The independent "visiting nurse" service cannot be reimbursed by the insurance policy under the central control of government.[41]

On the other hand, from the point of view of the elderly's family, there is a kind of tendency to place elderly patients in hospital, since in hospital all treatment is provided by the National and local government. (Vis. Law for the Health of Elderly, 1983). It is convenient for the supporting family to have its elderly family members in hospital because here there is easy accessibility to regular medical treatment, lack of housing space for totally bedridden elderly, and inexpensive cost. In the case of elderly dialysis patients, one of the family members (usually a non-employed female family member) becomes extraordinarily busy bringing the patient back and forth three times a week, and additional time for the dialysis treatment. This is one of the reasons dialysis centers have many available beds for hospitalization which were in the past fully occupied.

There are very few cases wherein a family member of an 80 year old kidney patient decides not to bring this person for treatment. According to a nurse in charge of dialysis, this is a very rare case. Generally speaking, Japanese family members who have elderly patients bring them in and ask what treatment should be done at the time. Later, they will be faced with continuous arrangements for treatment by dialysis. If there are no beds available under the government insurance plan, people will pay an additional amount to fill the gap between the cost of the insured bed and the private bed. (This system is called "Sagaku Choshyu" - collecting payment for the gap in costs.[42]

Kidney transplantation is available, but is not widely performed, due to the lack of available kidneys. Neocortical brain death criteria have not yet been accepted. However, in 1982, an advisory board on "life and ethics" was formed and attached to the Ministry of Welfare and Health; it is dealing with this issue of "brain death criteria" as one to be studied. There is also a special task force for determining "brain death;" it was established in 19083 as one of the advisory groups to the Ministry of Health and Welfare.[43]

Due to the absence of an officially policy decision -- except for professional criteria established by the Japanese Society of Brain Wave Research (Committee on Brain Death) in 1974 -- organ transplantation is proceeding rather slowly in order to avoid legal disputes over traditional notions of time of death.[44]

This is one of the unique phenomena in the Japanese situation, and has provided large numbers of organ donations (mainly kidneys) from living human bodies (Neomorts). As of December 1982, the total number of kidney transplantations was 2457, of which 1949 were from living donors and 508 were from cadavers.[45]

There are now nine active kidney transplantation information centers in Japan on which 3562 patients are registered as candidates for future kidney transplants. Retrieval searches were accomplished 84 times by May 1984, the opening date of this information system; 42,285 persons were

registered as possible kidney donors, according to the data provided by the Association for the Promotion of Kidney Transplantation. [37]

There have been several cases where kidneys were acquired from the U.S. due to the lack of available cadaver kidneys in Japan. In the case of two hospitals in Sendai City (Miyagi Prefecture in northern Japan), at Sendai Social Insurance Hospital and Tohoku University's 2nd Surgery Department, 33 cadaveric kidneys air-transported from the U.S. were used for transplantation as of December 1983. Since 1981, kidney transplants using cadaveric kidneys have increased compared to preceding years. One reason for this increase was the special arrangement to acquire cadaveric kidneys from the U.S.; another reason is the changing attitude of the public.[46]

However, there are large gaps between those who are waiting for kidney transplants and the actual transplants performed. Around 25-48% of the dialysis patients expressed their wish to have kidney transplants even though less than one percent of such transplants goes on annually.[47]

B. Nutritional Support

Nutritional support for elderly patients is generally one of the most well-provided life sustaining technologies in Japan. Some serious problems relating to nutritional support are: 1) cases of terminally ill, elderly patients; 2) cases of prolonged unconsciousness; and 3) cases where patients reject nutritional support.

1. The situations are very different from case to case in providing nutrition and/or hydration to terminally ill patients. All of these treatments have received endorsement by the Ministry of Welfare and Health and count in computing medical fee points. Only since early 1985 has nutrition support (by Central IV outside the hospital) been accepted as official medical treatment under the direction of physicians and operated by the patients themselves: 70 points (around U.S. 40 dollars) is counted for consultation and advising fee for this treatment (The Gov. Notice from the Director, Medical Service Section, Ministry of Welfare and Health, 18 Feb. 1985).

In the case of terminally ill cancer patients, symptomatic treatment, such as pain relief, should be done, while active and aggressive intervention, such as chemotherapy and radiation therapy, would be withheld. Because during this end stage of cancer both chemotherapy and radiation treatment usually cause side effects, and patients get weaker. IV nutrition support would also be undesired by many patients at this terminal stage. If "The Performance Status" is classified "under 3," all positive interventions would be regarded as more disadvantageous for the patient. Of course, there are very different cases even among patients classified P.S. 3 or P.S. 4 (see Table). The end-stage patient who is terminally ill and unconscious, should not be given aggressive medical intervention if it would only serve to prolong the dying process; this would violate the dignity of the patient as some physicians see it.[48]

Another physician, working in a pioneering Japanese "hospice," has mentioned that even the dying patient should receive nutritional support, including hydration, up to the last moment. Patients as well as family members who want to have the elderly patient live as long as possible should be given that opportunity, according to some physicians.[49]

2. Patients suffering prolonged unconsciousness are usually given nutritional support regardless of age and sex, as cases in Number 1. There are various causes for these kind of prolonged losses of consciousness; in many cases nutritional support would be given to these patients by naso-gastral tube, mouth, or IV. The nutritional support is given as part of the integrated treatment to the patient, but under the strict control of the medical care team.

3. Patients sometimes reject nutritional support by intentionally removing the naso-gastral tube or IV tubes. The rejection of any kind of medical treatment, know death will follow, is not common among Japanese patients, even though there now exists a patients' rights movement which claims patients are autonomous and have a right to reject treatment. Patients are expected to obey the physician and many health regulations reflect this paternalistic tradition. Unjustifiable rejection against the treatment given by physicians is supposed to be reported to the local authorities, under the Law for the Health of Elderly (1983); Articles 37 and 38 provide non-treatment and non-benefits for medical services

in cases where patients act "malicious" or intend criminal acts or where patients cause their own sickness or wounds due to misconduct like fighting and intoxication.

There are cases, such as the case of an elderly patient (83 years old, male), who was admitted to the ICU for treatment of shock caused by myocardial infarction and pulmonary edema. After one week of treatment, the patient had another shock, then he requested that all treatment cease and he removed all life-support tubes himself. Because of his clear diagnosis of fibrosis of the lung and the difficulties of his recovery, following tracheotomy, the patient was discharged from hospital; he died of dyspnea at home three days later. In this case it took 38 days of painful and aggressive treatment, including nutritional support at the penultimate stage, thanks to various technological interventions. The physician in charge of this patient had serious reservations, and expressed his doubt regarding the value of this expensive and aggressive treatment.[50]

Public debates in Japan are now taking place on various issues which relate to bioethical problems. One of the most important issues is the need for a coherent public policy on "brain death" in the context of the gradually=changing social values rooted in bio-technological achievements. The nutritional support technology should also be reexamined in terms of a patient's dignity and his right to medical treatment; it is a reasonable balance to the notion of

patient's autonomy for final medical and ethical decision making to have a peaceful dying process in more humane care environment without having aggressive, painful and extraordinarily expensive intervention.

C. Resuscitation

In the case of elderly, terminally ill cancer patients, there are rare cases where resuscitation is required. One of the reasons for resuscitation in Japan is the traditional attitude toward the dying patient who should be seen by his relatives at the moment of death. It is an important Japanese ceremonial event to have the closest persons at the bedside of a patient. So, in order to maintain this tradition, patients are resuscitated even though hopeless; sometimes this practice is accomplished with the ceremonial support of members of the medical and nursing hospital team.

According to a survey by the National Cancer Center of Japan, approximately 74% of dying patients had a resuscitation attempt.[51]

Age and sex have never been factors for deciding who should be resuscitated, whereas a complete diagnosis of a patient's medical status might reflect that the decision to resuscitate should be made with the patient's or family member's consent.

D. Ventilation

Mechanical ventilation is widely available in Japan. In many cases hospitals and nursing homes have the necessary equipment.

According to the amendment of a recent regulation issued by the director of the Medical Service Section, Ministry of Welfare and Health, Government of Japan (Notice No. 11, 18 Feb. 1985), ambulatory oxygen use at home by patients was officially endorsed and should be counted in the medical practice fee for 700 points (U.S. = 35 dollars.

This oxygen treatment would be given by the patients themselves, while at home, and mainly for those having chronic pulmonary problems but who are in rather stable condition when discharged from hospital. Physicians then, should be responsible for giving particular directions for home treatment by patients, and hospitals should be prepared to have these patients rehospitalized in case of emergency.

Because of the acceptance of this home treatment as official medical practice, the cost for the treatment is covered by health insurance according to the proportion required by each insurance scheme.[52]

Ventilation machine treatment in the ICU is very common, and expenses are also covered by insurance.

A Critical Care Committee has not yet been formed in many medical service institutions, and generally speaking physicians who are in charge of a particular patient's care and treatment

would decide what the medical treatment should be.

There are no common guidelines to be applied where ventilation treatment is in question.

E. Antibiotics

In Japan, chief causes of death have been drastically changing during the past ten years. Formerly, particularly before World War II, various infectious diseases were the common causes of death; now, various "geriatric diseases" are the chief causes of death.[53]

However, the causes of death in the elderly population, particularly at home, are called "Rosui," which means the "senility" and "weakness" caused by old age. In this case, it is quite common to have infectious diseases weaken the patient's physical condition and lead to weakness and death.

So-called "influenza" combined with secondary types of pneumonia, are increasingly high among the elderly in recent years. This clearly reveals the very sharp contrast of the infant and the elderly mortality due to influenza and/or penumonia.[54]

The use of "antibiotics" is very common for the treatment of influenza and pneumonia. However, in order to avoid the negative reaction of the elderly patient, a very careful selection of "antibiotics" should be made. Sometimes the prescription for "antibiotics" will be construed as a preventive treatment against pneumonia. The elderly are often

regarded as being a high risk group; some have suggested the elderly be given an injection to immunize against influenza, but on a voluntary basis.[55]

In the case of terminally ill cancer patients, the statistical data show that antibiotics are commonly used for symptomatic treatment (see Table). These data were gathered at the hospital of the National Cancer Center of Japan during six months between June and November 1982. The 228 patients died because of malignant tumors, among which 191 are shown in Table 8. Chemotherapy was given to 48.4% of the patients, and antibiotics were used in 75.5% of the cases. In most terminal patients, the positive intervention by the medical team for prolonging life has been going on frequently. Only 29% of the patients at this hospital with terminal cancer had symptomatic treatment rather than aggressive intervention.[56]

All of these medical interventions require chemotherapy as well as surgical interventions and were done within one month of the patient's death. It is frequently necessary to refrain from positive and aggressive medical treatment if the patient's situation and symptoms do not bring about a reduction of pain or amelioration of the disease.[57]

V. Concluding Remarks

The Japanese are now facing both a radical change in traditional values, including attitudes toward health and rapid technological changes which call for everything possible to be applied in the clinical medical setting.

Technological interventions -- such as life sustaining technologies -- now impact on other issues of economics, ethics, and public policy.

By emphasizing Japan's traditional value system and value of family and communal relationships, which more and more influence everyone's daily lives, a new and fundamental shift in health and medical policy making is taking place though initiated by government policy planners of the Health and Welfare Ministry. Yet there is not enough public involvement. Elderly people are now expected to pay for increasing costs and to share as is now required by the recent amendment of the Law for the Health of the Elderly. Those who are insured in Health Insurance Societies, under government control, are now obligated to pay 10% of the total cost of medical treatment, which had been free of charge since 1927.[58] On the other hand, and in the name of cost containment goals, private patient incentives are now being introduced. Multinational health and medical industries, as well as large insurance corporations, are currently seeking to expand their market in Japan -- a policy which is unprecedented.[59]

This critical turning point in Japan's health policy requires the Japanese public to take a more active role, to participate in open debate in order to achieve an secure an excellent level of health and medical services in Japan.

Foot notes

1. Statistics and Information Department, Ministry of Health and Welfare, Government of Japan, ed.,Health and Welfare Statistics in Japan, Health and Welfare Statistics in Japan (Health and Welfare Statistics Association, Tokyo,1985) p.20.
2. Yoshizawa,T., Shinia Raifu Hyakka (Senior Life Encyclopedia), Shakai Hoken Kohosha, Tokyo 1982, pp.74-75
3. Ministry of Wefare and Health,Showa 59 Nen Kan-i Seimei Hyo (Simplified Table for Life Statistics,1984),Government of Japan,1985 p.33.
4. Nakamura, E., On the death at homes and institutions, in "IRYO'85" (Medical Services '85) Vol.1,No.5,Sep.1985, Medikaru Furendo Sha, Tokyo,1983,pp.118-119.
5. Okayasu,M.,ed., Sogoenjyo toshiteno Taaminaru Kea (The terminal Care as an integrated support system), Chiimu Iryo,Tokyo 1983, p.259
6. Ministry of Welfare and Health, Analysis of Brain Death Cases, Koseisho, Tokyo, 1985
7. Ministry of Welfare and Health, The Report of Study Group concerning Brain Death, Koseisho, Tokyo,1985.
8. General legal trends and court cases in Japan relating to malpractice suits affirms the physician's responsibility in giving information to the patients (Ishi no Setsumei gimu which means physician's obligation for explanation in doing treatment) as well as to receive consent.However in several cases the Japanese courts is still holding "prerogative right of medical discretion"to be given to physicians which shows inconsistency in dealing the medical malpractice suits. See cases,Osaka Dst.Court(Nov.15,1979),Sapporo

District Cout(Dec.221978),Tokyo Districct Cout(Dec.21,1981) and Hiroshima District Court(Dec. 22,1982).In the court case in Hiroshima, the decision has mentioned that there was no malfeasance in physician's "non-explanation" on side effects of "schock death" to be caused by injection of streptmycin as it would give unnecessary anxiety to the patient. Also, in recent case in Tokyo High Court (April.22,1985) gave the negative decision to allow the patient's autonomy for the medical treatment by having physician's explanation. This decision says " Medical treatment is solely the responsibility of physician because of highly professional character and the phsycians are obliged to do medical treatment in having his/her own confidence according to medical standard -----an appropriate medical treatment as a professional technique could hardly be done if physicians are always supposed to confirm the consent of the patient by following the patient's own chices"(Hanrei Jiho,No.1159,p.90,1985).

9. Kimura, R., Baioeshikkusu to Byoin no Kino(Bioethics and the Funstion of Hospital), Japanese Journal of Hospital,Vol.vol.40, No.1,pp.50-53 and also recent development of the "Patients' Rights" in Japan should be mentioned here. see National Committee on Patients' Rights, Kanjya no Kenri Sengen (An), (The draft of the Declaration of Patients' Rights. Suzuki, T., Kanjya no Kenri Sengen,(Declaration of Patients' Rights), in "Jyurisuto" No.826,Dec.1,1984,Yuhikaku,Tokyo pp.48-51.

10. Okada, K., Sosei o shinai kijyun (Standard for DNR) in "Saishin Iryo to Rinri"(The recent medical service and ethics) ed.,by Aochi, O.,Herusu Shuppan,Tokyo,1985

11. Hara,Y. and Chihara,S.,Hosupisu kea (Hospice Care),Medikaru Furendo Sha,Tokyo,1983,,p.80

12. Inagaki, T. The cases of Physician's rights(prerogative) in the medical treatment,Iryokago Sosho no Riron (A Theory of Malpractice Suits),Nippon Hyoron Sha,Tokyo,1985,pp.64-65

13. Nakai,Y.et.al., Iryokagoho Nyumon (An Introduction to the Law relating to Medical Malpractice), Seirinshin Shinsha,Tokyo,1979, pp.3-26.

14. According to the data by Supreme Court, the medical malpractice suits now in pending are 1329 cases in the year 1984 and since 1974,there have been around 250 cases in average in each year till 1984.

15. Nakai,Y. op.cit.,pp.180-181
As of year 197o,the medical malpractice trouble has has 1986 cases and and 1038 cases were solved by the arrangement of "Conflicts resolution Committee of the each local prefecutural medical Association" (Journal of Japan Medical Association,Vol.68,No.2, 1970,p.183). This data shows that the general trends of Japanese approach in conflicts resolution outside courts.
Even the malpractice suit would have been brought to the court, the final decisions were not made by court ruling but "Wakai" (The settlement of the conflicts by the initiative of the court by having mutual agreement between the defendant and the plaintif).This "Wakai" settlement has various reasons to be adopted by the parties as follows. 1.Tendency to avoid the losing the case in the physician's side for keeping their credit,reputation and honor. 2. The defendant's wishes for expedicious settlement than normal court procedure , and 3.Judge's inclination to avoid court ruling because of highly professional character of the cases.

16. Suzuki,T. Shijyutsu Shodakusho to Kanjya no Kenri(The Consent Form for surgerical operation and patients' rights) in Iatorosu No.4,pp.70-71.

There are three types of "Consent Form" presently used in the public hospitals in Japan. Patients or their proxies are requested to sighn with seal in the document stated as 1.no-complaint whatsoever anything happen during or after operation and causing no trouble to the hospital,2.understood and gave consent in having full explanatic on surgery (Operation, anastesia and treatment) and 3. asking all kind of treatment to the physicians in charge base on the explanatin and understanding in present situation of sickness, necessity for operation , pregnosis and possible complications.

17. Suzuki.op.cit.,p.70

18. Fujita,K.,Songenshi Rippoka no Doko to Mondaiten(The trends and some points of problems relating to the legislation for the dignity of Death) in Rippo to Chosa (Legislation and Research) No.98, June, 1980.pp.10-13.

19. Fujita,K., op.cit. p.12.

20. Fujita,K., op. cit., p.16

21. Nishida,H.,Seimeisosateki handan to sogoteki Iryo no Jyuyosei nitsuite (Life-manipulative judgement and the importance of intergrated medical services)in Symposium report II on the hereditary malformity and it's treatment,1982.Tokyo,p70.

22. Nishida ,H.,Sakamoto,S.,and Sakanoue,M.,Shusanki no Rinri(Ethics of perinatal period),in Sanfujinka no Sekai (The World of Obsterics and Gynecology). Vol.37, special issue,1983

23. Hara,Y., op.cit.76-80

24. Kaibara, E. Yojyokun(The Teaching for Keeping Health),1714(English translation by Kunihiro,M.,1974.pp.199-133

and also Fujikawa,Y.Nihon Igaku Shi(The History of Japanese Medicine),194o,Tokyo.

25. Lock, M.M.,East Asian Medicine in Urban Japan, Varieties of Medical Experience,California Univ.Press.pp.111-178
26. Anma massage Shiatsushi,Harishi,Kyushito nikansuru Horitsu (The law relating to Anma Massagist,Shiatsuist,Acupuncurist and Mxabustionist etc.),1947, Dec. 20th, The Law No.217 Government of Japan.
27. Kimura, R. Health Care for the Elderly in Japan in Health Policy, Ethics and Human Values, An International Dialogue, Ed.by Bankowski Z. and Bryant J.H., Council for International Organizations of Medical Sciences,Geneve,1985. pp.184-193.
28. Kimura, op.cit.,p.187
29. Hino,S.,et..al. ed., Nihon no Hokeniryo(The Japanese Health & Medical Services).Rodojyunposha,Tokyo,1984.pp.24-25.
30. Kikuchi,T.,Jibuntachide Inochi o mamotta Mura(The Villege which people themselves had an initiatives to maintain & promote their Health and Life),pp.82-151 also Hino.H.,et.al. op.cit.p.182
31. Hino,H. et.al. op.cit.p.183
32. Hino,S.,Gendai Nihon no Iroseisaku(The Policy for Medical Services in Contemporary Japan) Rodojyunposha,1984.pp.70-88.
33. Hino.S.et al. ed. p.178
34. Hino.S.op.cit.p.70.
35. Ogishima,H.,et. al., Rojin Hoken Ho to Rojin Iryo no Shinten (Law for the Health and Medical Services and the Development of Medical Services for the Aged),Japanese Journal of Nursing,Vol.48. No.7. Aug.1984
36. Ministry of Health and Welfare (Koseisho),Government of Japan, Health and Welfare Services in Japan,1984. p.23.

37. Jinko Toseki Kenkyu Kai(The Society for the Study of Artificial Dialysis) Kodaka,M.,Wagakuni no Toseki Ryoho no Genkyo (Present Situation of the Chronicle Dialysis Treatment in Japan) pp.34-35.

38. Sakai,T.,CAPD Ryoho o meguru Shomondai (Several Problems relating to CAPD Treatment) inAnnual Report, Kidney Center, Kitasato University Hospital , Part 3.1984.pp.2-6.

39. Sakai,T., op.cit.,p.2

40. Ministry of Welfare,Medical Service section's Notice on Feb. 1984.

41. Sato, A., Ikiru soshite Shinu to yukoto (On Living and Dying), Keizaioraisha,1985. pp.225-226.

42. Niki,R.,Irokeizaigaku(Medical Economics),Igakushoin,1985.pp.212-214

43. Otani,M., Noshi-Horitsu no tachiba yori (Brain death- From the legal Perspective in Chiryogaku(Biomedicine and Therapeutics) Vol.14 No.4 pp.499-502 ,1985

44. Yokoyama,T.,Shitaijinishoku to sono sisutemu (Cadervaric Renal Transplantation and Renal Transplantation Information Systems) in Chiryogaku(Biomedicine and Therapeutics) Vol.13 No.375-378.1984

45. Yokoyama,T., op.cit.,pp.377-378.

46. Sasaki,T.,et.al.Kuyu Beikoku Shitaijinishoku no Genkyo (Current Status of Cadaver Transplants using Kidneys shipped from the United States) in Chirogaku(Biomedicine & Therapeutics) Vol.13 No.3.1984

47. Iwasaki,Y., Zokiteikyosha o meguru Shomondai (Some Problems concerning to Organ Doners) in Chiryogaku (Biomedicine and Therapeutics) Vol.13. No.3. pp.396-400.1984

48. Ishikawa,S., Yoriyoi Shi towa (Better Death----?)Iryo (The Medical Services) Vol.1 No.5.pp.20-21,1985

49. Hara,Y.,op.cit.p.80

50.Aochi,O.,Saishin Iryo to Rinri (Recent Medical Services and Ethics) Herusu Shuppan, 1985.p.130

51. Kakikawa,F., Kango no tachiba kara-Kyukyu Iro niokeru Seimei to Rinri nikansuru furii tokingu(The Nursing Point of View-Free Talking on Life and Ethics in Emergency Medical Services) in Aochi,O.,opcit. p.149

52. Ministry of Health and Welfare, Medical Service Section's Notice, No.11. 18th, Feb.1985

53. Health and Welfare Statistics Association, Health and Welfare Statistics in Japan, 1985,pp.49-50.

54. Health and Welfare Statistics Association, op.cit.,p.51

55. Amano,H.Koseizai no Rojin eno Karyotoyo wa Kinmotsu (The Overdose of The Antibiotics to the Elderly is hazardous) in Nikkei Medical, No.187,Oct.1985.pp.65-68.

56. Mizuguchi,K.,and Hiraga,I.,Makkikanjya no nidu to Taio (The Needs of the Terminal Patients and the Response to Them). in Sei to Shi no Iryo
(Medical Service for Life and Death),Asakurashoten,1985,pp.136-140.

57. Mizuguchi,K.,op.cit.p.138

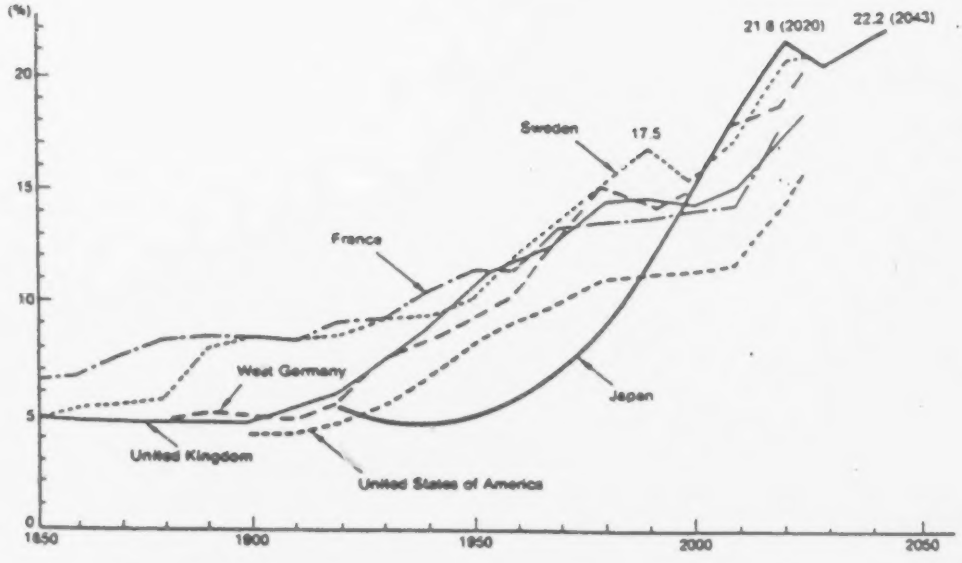
58. Kenkohokenho(Health Insurance Law) Amended and enforced from 1st, Oct.1984.

59. Hino.S.,op.cit.,90-151

In 19[illegible] the number of those aged 65 and over was 4,155,000 only 4.9% of the total population. That is, during the 31 years since 1950, the number of those of 65 and over had increased 2.6 times, and the ratio of the aged to the total population had increased rapidly. This tendency is expected to continue, and it is estimated that at the beginning of the 21st century, the total number of those aged 65 and over will exceed 20,000,000, and account for more than 15% of the total population.

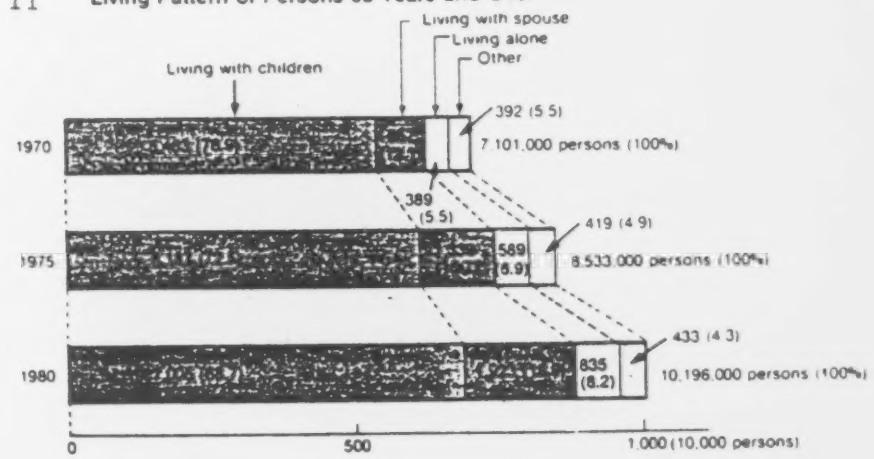
Chart I

Trend of the Ratio of the Aged (65 years and over) to the Total Population



Source: For Japan, from Satistics Bureau, Prime Minister's Office and Population Problems Research Institute of Ministry of Health and Welfare
For other countries, from UN

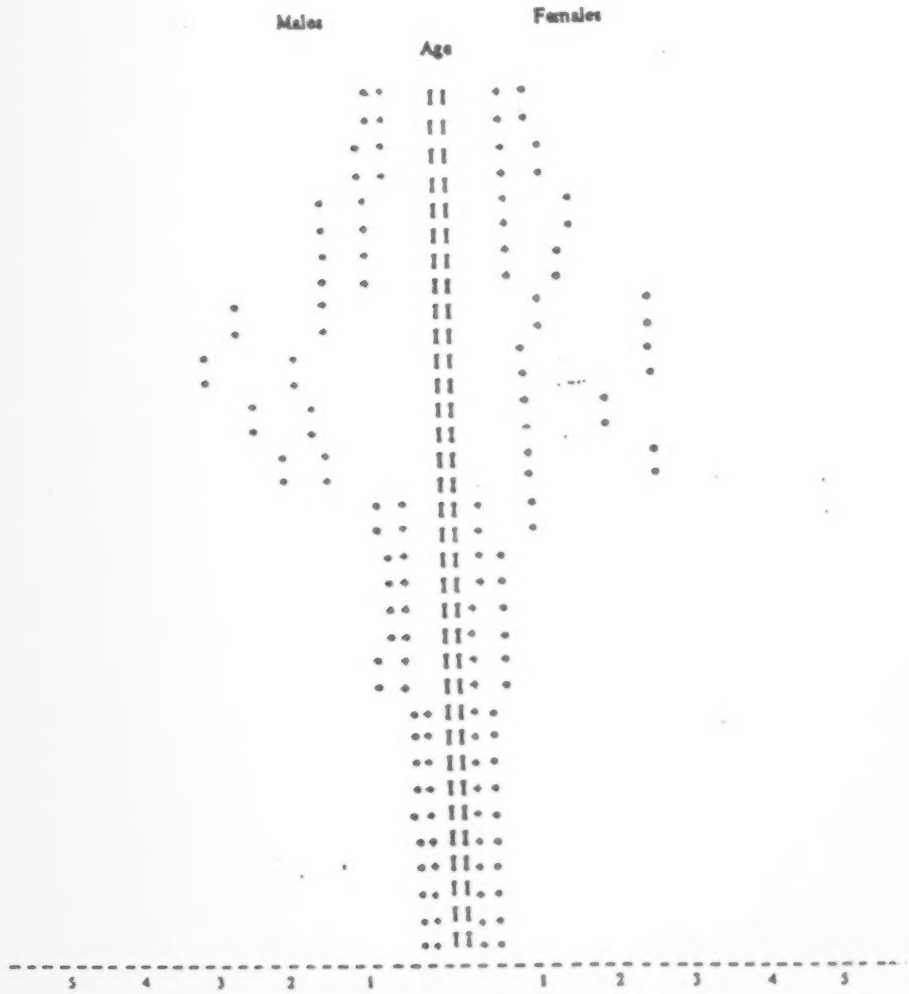
Chart II **Living Pattern of Persons 65 Years and Over**



Source Statistics Bureau, Prime Minister's Office
Note Both actual number and proportion are those of ordinary households, not including quasi-households

Chart III

Estimated number of hospital patients and in-patients by age and sex per day in 1980



(Unit: 15,000 persons)

• Hospital patients
+ Hospital in-patients

Chart IV

Estimated number of hospital patients and in-patients by age and sex per day in 2025

(Unit: 15,000 persons)

• Hospital patients
• Hospital in-patients

Table I.

Population · future population projected · percentage distribution by three broad age groups and sex, 1920-2075

Both sexes

	Population in 1000				Percentage distribution			
	All ages	0~14 years old	15~64	65 years and over	All ages	0~14 years old	15~64	65 years and over
1920	55 963	20 416	32 605	2 941	100.0	36.5	58.3	5.3
1925	59 737	21 924	34 792	3 021	100.0	36.7	58.2	5.1
1930	64 450	23 579	37 807	3 064	100.0	36.6	58.7	4.8
1935	69 254	25 545	40 484	3 225	100.0	36.9	58.5	4.7
1940	71 933	26 383	42 096	3 454	100.0	36.7	58.5	4.8
1947	78 101	27 573	46 783	3 745	100.0	35.3	59.9	4.8
1950	83 200	29 428	49 658	4 109	100.0	35.4	59.7	4.9
1955	89 276	29 798	54 729	4 747	100.0	33.4	61.3	5.3
1960	93 419	28 067	60 002	5 350	100.0	30.0	64.2	5.7
1965	98 275	25 166	66 928	6 181	100.0	25.6	68.1	6.3
1970	103 720	24 823	71 566	7 331	100.0	23.9	69.0	7.1
1975	111 940	27 221	75 807	8 865	100.0	24.3	67.7	7.9
1980	117 060	27 507	78 835	10 647	100.0	23.5	67.3	9.1
	Future population projected							
1985	120 301	25 737	82 366	12 198	100.0	21.4	68.5	10.1
1990	122 834	22 512	86 032	14 290	100.0	18.3	70.0	11.6
1995	125 383	21 405	86 897	17 082	100.0	17.1	69.3	13.6
2000	128 119	22 561	85 615	19 943	100.0	17.6	66.8	15.6
2005	130 008	23 941	83 839	22 228	100.0	18.4	64.5	17.1
2010	130 276	23 858	81 940	24 478	100.0	18.3	62.9	18.8
2015	129 332	22 427	79 593	27 311	100.0	17.3	61.5	21.1
2020	128 115	21 419	78 747	27 950	100.0	16.7	61.5	21.8
2025	127 184	21 929	78 176	27 079	100.0	17.2	61.5	21.3
2050	120 790	21 909	73 375	25 506	100.0	18.1	60.8	21.1
2075	118 395	22 141	73 000	23 253	100.0	18.7	61.7	19.6

Note; ·Population census 1920-1980
·Excluding Okinawa-ken for 1947-1970

Sources; "Population estimates of Japan"
"1970 Population census of Japan"
"1975 Population census of Japan"
"1980 Population census of Japan"
Statistics Bureau, Prime Minister's Office,
Institute of Population Problems, MHW
"Future population projected for Japan by sex and age for 1980 to 2080
Prepared in november 1981"→Medium projections of future population as of October 1 of the year stated prepared as of November 1981

Table 2.

Future changes in selected social security-related indicators, 1980-2025

Year	Social security benefit (billion yen)	Social security benefit / National income (per cent)	Tax revenue / National income (per cent)	Social security contribution / National income (per cent)	Social security contribution + Tax revenue / National income (per cent)
1980	23 842	12.46	21.89	9.45	31.35
1985	40 288	14.09	23.02	10.89	33.92
1990	68 814	16.31	23.79	12.64	36.44
1995	121 273	20.00	24.00	15.48	39.49
2000	214 038	24.73	23.56	18.88	42.45
2005	373 273	30.23	23.92	22.20	46.12
2010	660 470	36.31	23.42	28.17	51.60
2015	1 122 703	43.21	23.19	34.62	57.81
2020	1 558 375	46.99	23.31	38.21	61.53
2025	1 970 066	48.70	23.36	39.94	63.30

Table 218. Changes in medical services required per day, 1980-2025

Year	Number of hospitals	Number of hospital beds	Number of clinics	Number of clinic beds	Number of dentists
1980	8 599	1 260 648	74 112	279 897	35 674
1985	9 297	1 385 868	78 469	307 332	36 738
1990	10 058	1 520 508	83 280	339 635	37 524
1995	10 919	1 667 589	89 544	376 426	38 302
2000	11 725	1 809 365	96 159	414 119	38 928
2005	12 350	1 929 240	101 366	447 054	39 266
2010	12 716	2 011 731	104 055	468 822	38 903
2015	12 956	2 072 469	105 505	487 398	37 953
2020	13 132	2 118 254	106 704	508 031	37 049
2025	13 061	2 120 696	106 399	513 912	36 265

LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY

LEGAL ISSUES

CANADA

HOLLY DUGAN

JOHNS HOPKINS CENTER ON AGING

CANADA

FINANCING OF HEALTH CARE

Federal-Provincial Roles

In 1867, all powers for the "peace, order and good government" were assigned to the Government of Canada by an act of the British Parliament, the British North America Act. A list of powers was assigned exclusively to the ten Provinces. Neither "health" nor "welfare" was explicitly mentioned. However, hospitals, asylums and charitable institutions in and for a Province fall under Provincial responsibility. Separate Federal responsibility was assumed for quarantine and marine hospitals. Hatcher (1) attributes the continued Provincial power over and responsibility for health services to Quebequois separatism which from 1800 on fought for religious liberty, use of the French language and the assimilation of French civil law into the Quebec Act. From 1900 on Quebec performed, according to Hatcher, the function of the U.S. "Solid South" to the Liberal Party in Canada. On only four occasions was a government voted in without the support of the Quebec Members of Parliament.

Concern with possible infringements on Provincial rights, a notion inspired by the Quebequois, carried forward to 1941 when efforts failed to pass national health legislation which was similar to the U. S. Medicare model. As a result, conditional Federal grants for Provincial health insurance were

proposed but disagreement on financing formulae and tax jurisdictions likewise doomed this attempt.

In 1948 the Government of Canada (GOC) introduced a series of Grants-in-Aid which were earmarked for hospital construction, traditional public health services, research and training. Most of these required matching funds and were based on priorities defined by GOC which set the stage for continued involvement of the Dominion in Provincial standards for health services, drugs, biologicals and various policy issues such as "certification of need" for new hospital construction.

In the meantime, the Provinces began to introduce their own health insurance programs, Saskatchewan at the fore (in 1947) while, at the same time, private health insurance plans began to crop up. In 1955 Ontario asked for Federal support to introduce a universal health insurance program and in 1958 the Dominion passed the Hospital Insurance and Diagnostic Services Act (2) offering to reimburse any Province for one half the cost of hospital insurance programs to include universal coverage, "comprehensive benefits", uniform accounting practices and statistical and fiscal reports to the Federal Government. "Comprehensive benefits" provided for short term inpatient and all outpatient care exclusive of psychiatric hospitals, TB sanitoria, custodial care and nursing homes. All the Provinces accepted the Grants by 1958 except Quebec which did not accept Federal support until 1961.

The principal Federal agency in the field of health care is the Department of National Health and Welfare which assists

Provincial health departments and deals with various health matters outside the range of the Provinces. The Health Protection Branch of the Government of Canada concerns itself with adequate standards in foods, drugs, cosmetics and medical devices, as well as environmental factors and control of communicable diseases. The Health Services and Promotion Branch is the branch which is concerned with the administration of federal aspects of provincial hospitals, insurance programs, research and training grants. Yet another branch, the Medical Services Branch, provides medical and health services for Indians and residents of the Yukon and the Northwest Territories as well as quarantine, immigration medical service and advises on health care for those in civil aviation.

In 1977 the method of reimbursing for 50 per cent of the cost of insured services was renegotiated to allow for reimbursement for alternatives to acute hospital care and to align Federal expenditure with gross national product and the fiscal resources of individual Provinces (3).

GOC began making additional per capita cash contributions toward the cost of nursing home intermediate care, adult residential care, converted mental hospitals, health aspects of home care and ambulatory health care services. The Canadian Assistance Plan provides Federal funds for 50 per cent of health care services for extended care not covered by the national health insurance programs and for persons of proved financial need.

Under the Hospital Insurance and Diagnostic Services Act, a Federal-provincial agreement, all residents are provided on a pre-payment or tax-financed basis standard-ward accomodation and normal hospital services. These agreements are supplemented or extended by the individual provinces such as Nova Scotia covering mental health services. Ontario provides ambulance service, physiotherapy and long term care. Manitoba covers extended care, personal care and hostel care and Alberta provides nursing home care.(4)

Payment of premiums for Federal-Provincial Hospital Insurance is required in Ontario and Alberta for families able to pay. The financing of insured hospital services in Newfoundland, Prince Edward Island, New Brunswick, Saskatchewan, Manitoba and the two territories is entirely from general tax revenues. Nova Scotia supplements general revenues with a sales tax. Quebec has a surcharge on income tax and an employer-paid tax on wages and salaries which helps to finance hospital insurance programs. Ontario residents are required to pay an annual premium. In Alberta an annual premium is levied on single persons and families of two or more persons. In Alberta, British Columbia and Quebec patients are charged authorized fees at the time of service which are deductible from provincial payments to hospitals.

HEALTH CARE FINANCING FOR THE ELDERLY

The responsibility for comprehensive health care for the elderly rests with the provinces (5). In those provinces where health care provision is based on the payment of a premium (e.g.

Ontario) the aged pay no premium. Universal long term care benefits based on functional impairment are provided by most Canadian provinces. There is no means test for these benefits. In provinces where copayments are levied, these are set at a rate designed to "leave even the poorest pensioner with a small disposable income" (6). For instance, in Ontario in 1984 the fixed room charge for nursing home care was $15.68 per day. According to Kane and Kane (6), this left $96 per month disposable income for those persons entirely reliant on government income maintenance.

FOREGOING TREATMENT

CONSENT

Part IV of the Canadian Criminal Code outlines Offenses Against the Person in which it is stated that treatment performed without a legally effective consent constitutes an assault (7). However in most cases authorization to treat is granted under provincial or mental health legislation (8).

Canadian Common Law traditionally presumes the only justification for medical intervention to be consent, therapeutic benefit, appropriate medical skills and knowledge and lawful justification. The latter expression applies to some prohibited procedures such as organ transplants. However Sections 45 and 198 of Part I of the Canadian Criminal Code effectively make surgical and medical treatment legally valid provided that the doctor has reasonable skill and knowledge, exercises reasonable care, that it is reasonable to perform the

operation and that it is for the benefit of the patient (9). Section 198 of the Criminal Code reads

> Every one who undertakes to administer surgical or medical treatment to another person or to do any other lawful act that may endanger life of another person is, except in cases of necessity, under a legal duty to have and to use reasonable knowledge, skill and care in doing so.

LIMITATIONS

Limitations on an individual's right to forego treatment are implicit in the Canadian Criminal Code Section 199 which states

> Every one who undertakes to do an act is under a legal duty to do it if an omission to do the act is or may be dangerous to life.

thus requiring everyone who undertakes to administer surgical or medical treatment to continue it if omission might endanger the life of the patient.

The fundamental right of an individual to the security of his person was said to be the first right of English Law and in 1960 was declared the first right of the Canadian Bill of Rights. It means not only the protection of one's physical integrity but the provision of necessaries for its support.

The Criminal Code upholds an individual's right to refuse treatment with some exceptions such as compulsory treatment for alcohol or drug abuse (10), the ordering of a mental examination

(11), ordering the custody of insane persons (12), and the mentally ill (13). The right to refuse intrusion on one's body has been upheld in case law (14). Nonetheless, denial of the right to refuse when refusal may result in death is "based on the priority of the preservation of life over the autonomy of the individual (15)."

In an article entitled "The Right to Refuse Treatment: Commonwealth Development and Issues" , authors Gordon and Verdun-Jones(8) state that the recent (1982) Canadian Charter of Rights and Freedoms could "mark the rebirth of judicial activism" although they predict that the Canadian Supreme Court will be conservative in their initial approach to cases involving violations of these rights and freedoms. Gordon mentions two cases which illustrate the kind of negligence involved in treating without informed consent, Reible v. Highes (1980) 114 DLR (3rd)1 and Hopp v. Lepp (1980) 112 DLR (3rd)67. Gordon and Verdun-Jones claim that the right to refuse treatment in mental health settings is virtually non-existent in Canada, Australia, New Zealand, England and Scotland. They quote I. Kennedy Criminal Law Review 217 (1976) as saying "the right to self-determination in medical treatment situations, when this means refusing medical care, is confined within. . . ill defined bonds." In the case of psychiatric treatment without the patient's consent, requests to treat can be made to the Regional Review Boad under Section 35 of the Mental Health Act. A similar provision under Section 46 of the Nova Scotia Hospitals Act stipulates that no person admitted to a hospital shall

receive treatment unless he or she consent to such treatment excepting those "incapable of consenting." Incapacity to consent is assessed by the attending psychiatrist by virtue of Section 44 of the same Act (8).

In the 1982 Canadian Law Reform Commission paper, the current legal dilemma with regard to refusal of treatment is clearly summarized. "present law, because of the distinctions which it makes between the act and omission and becuase in theory it requires the continuation of any treatment undertaken if its interruption constitutes a threat to life, clearly promotes certain biases in favour of heroic or aggressive treatment, or at least creates a legal climate likely to encourage this approach" (15). For this reason there has been a tightening of policy at the provincial, local and institutional levels.

SUICIDE

According to the Canadian Law Review Commission Working Paper #28 entitled Euthanasia, etc. (15), attempted suicide has recently been decriminalized in Canada. It might be useful to separate suicide into two concepts, that of commission and omission. Commission of the act (e.g., shooting, hanging or poisoning oneself) is not a criminal offense, suicide having been recently decriminalized in Canada (15). Suicide by omission (the refusal of treatment) is ostensibly protected under section 244 of the Criminal Code which states

> A person commits an assault when. . . without the consent of another person or with consent that is obtained by fraud, he applies force intentionally to the person of the other. . ."

Unconsented medical treatment is thereby illegal except in emergencies and "every medical interference with the body of another is an assault." (17) Although consent must be freely given there is no mention in the law of "informed" consent. In spite of cases which recognize the right to refuse treatment (14) and those supporting the individual's right to make unreasonable or foolish choices (18), the Criminal Code is not explicit in respect to parties to a suicide resulting from omission (termination) of treatment.

INCOMPETENCE

The earlier discussion of limitations on the rights of mental patients suggests that the incompetent patient falls under local or provincial jurisdiction and even institutional authority as in the Dependent Adults Act of Alberta.

The patient must have the ability to understand that to which he or she consents. The patient must have at least a general perception of what is happening and what might result. In the case of incapacity to make treatment decisions, the disability is a legal one in the case of minors and a mental one in the case of the elderly. It is in the latter instance a subjective test. If the first question is whether the patient is competent, the second question is who should assess his

competence, and even more important who should decide for him be he judged incompetent. Working Paper 26 recommends that "the ultimate finding of incompetence should be made by a court" and states that in most provincial legislations this is indeed the case (15).

The Law Reform Commission recommended the use of administrative boards to decide what is in the best interest of the incompetent patient in regard to cessation of treatment suggesting that the family's interests and those of the patient are not always in accord.

In practice hospitals are increasingly adopting policies such as the Massachusetts General Hospital's "Optimum Care for Hopelessly Ill Patients" (19). In Canada, the very general "Joint Statement on Terminal Illness" is the product of a working party of the Canadian Nurses Association, the Canadian Medical Association and the Canadian Hospital Association in cooperation with the Candian Bar Association. It is based on the Canadian Medical Association's "Statement on Terminal Illness" (20) and was drafted with the advice of the Catholic Health Association and the Law Reform Commission of Canada. This statement sets forth policy and procedures for deciding whether " compassionate palliative care only" is called for in which case a "no resuscitation" order is placed on the patient's record. This statement appears to indicate surrogate decision making for the incompetent patient would involve the attending physician, nursing staff and the family.

A draft of the Misericordia Hospital (Alberta) Policy on

Resuscitative Interventions for the Terminally Ill (November, 1984) based on the above mentioned Joint Statement calls for a procedure of clear communication between patient, family and clinical staff, documentation in patient records and consultation with the Bioethics Consultative Services Group.

In respect to formal legislation at the provincial level, there is provision for guardianships in the case of incompetence. The appointment of a guardian or public guardian is by court order (21). A forthcoming book on this subject by Robert Gordon, Simon Verdun-Jones (Simon Fraser University) and Don MacDougall (University of British Columbia) will set out the central problem in this area of the law (self-determination v. paternalistic intervention).

(current status of living will legislation in Canada to be added)

LIABILITY

According to the Law Reform Commission's Working Paper No. 28 (16), there is no instance in case law of a doctor's being convicted of terminating a patient's life with drugs. Likewise, no case of withdrawing treatment from a dying patient has ever led to conviction. This lack of legal precedent indicates that there is a certain dependence on the disposition of the Crown which is difficult to predict. It is not inconceivable that provisions in the present Criminal Code of Canada could be interpreted to imply criminal liability in cases of cessation of treatment.

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However, under Part I in the general part of the Criminal Code, acts which may be criminal are protected if they offer a benefit to society at large. In the case of medical treatment, these acts fall into the category of "protection of persons in authority." However, the concept of "authority" in the Criminal Code is not entirely applicable to doctor-patient relationships, according to the Law Reform Commission researchers. In Working Paper No. 26(15), the doctor is described as a person who has no duty to protect others "unless he has directly or indirectly undertaken to do so."

The Criminal Code, section 45, states that "every one is protected from criminal responsibility for performing a surgical operation upon any person for the benefit of that person if

a) the operation is performed with reasonable care and skill, and

b) it is reasonable to perform the operation, having regard to the state of health of the person at the time the operation is performed and to all the circumstances of the case."

Under the law, a further offense is the failure to provide the necessaries of life to someone under one's charge if failure to do so endangers life and, in addition, to continue to treat unless by the patient's consent and in a suitable time frame a doctor may withdraw from the case. The causing of bodily harm with intent is an offense regardless of consent and the failure to perform a duty which results in death or bodily injury is criminal negligence. In Working Paper 26, the authors

state that murder or manslaughter rarely apply to medical treatment "except in the case of cessation of life-saving treatment and the decision not to administer life-saving treatment." (See Section 199 of the Criminal Code cited above.)

The Law Reform Commission on Medical Treatment and the Law (15) suggests that the administration of treatment continue to be regulated by the Criminal Code but be distinguished from certain other acts of application of force which are considered to be criminal.

Further development of hospital policy on "compassionate and palliative care only" and local legislation on the right to refuse treatment, living wills and death with dignity may affect the issue of physician liability but it is doubtful that the exculpation will be complete in all cases.

INFLUENCE OF RELIGION

Predominant religions in Canada are Anglican (Protestant) and Catholic from the British and French settlers, respectively. Keyserlingk (22) argues a basic agreement between Protestant and Catholic viewpoints with respect to the sanctity of life principle. He cites Norman St. John-Stevas (23) and Paul Ramsey (24) to support the vitalist point of view. The so-called "vitalist" perspective is that control over human destiny ought to be left to God or nature and that no matter what the condition of the patient, it would be contrary to the sanctity of life principle "to preserve it or interfere with it"(22).

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Beyond the vitalist viewpoint, however, is the concept of "quality of life" which sparks continual and irreconcilable debate. The current tendency toward decisions regarding the quality of life marks a paradigmatic shift that is not yet universally accepted. Evidence of the trend can be seen in the statements below.

Pope Pius XII (1957):

> "But normally one is held to use only ordinary means -- according to circumstances of persons, places, times and culture -- that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. . .

From the Medico-Moreal Guide of Canadian (Roman Catholic) Bishops in 1970:

> (Art. 9) "Every human being has a right to live, and every effort should be made to protect that right. (Art. 10) However, man is not bound to have recourse to every means to prolong life. Neither the patient nor the doctor is obligated to resort to involved techniques for artificial survival."

From Ethical and Religious Directives for (U.S.) Catholic Health Facilities in 1971:

> (Art. 28) "Euthanasia ('mercy killing') in all its forms is forbidden. The failure to supply the ordinary means of preserving life is equivalent to euthanasia. However,

neither the physician nor the patient is obligated to the use of extraordinary means."

From the American Medical Association in 1973:

"The cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that death is imminent is the decision of the patient and/or his immediate family."

From the Canadian Medical Association in 1975:

(Art. 18) "An ethical physician will allow death to occur with dignity and comfort when death of the body appears to be inevitable;

(Art. 19) An ethical physician may support the body when clinical death of the brain has occurred, but need not prolong life by unusual or heroic means."

One conclusion that may be drawn here is that while religion may influence individuals, it no longer appears to have significant impact on legislative decisions or the policies of institutions. However, the full impact of the Catholic Archdiocese Document on War and Peace of November 1983 has not yet been felt. Also, the work of Cardinal Bernardin of Chicago will no doubt have longreaching effects in support of consistent ethics of life and quality of life. Likewise, the influence of fundamentalist and right-to-life views currently being expressed in the U.S. remains to be assessed.

REFERENCES

(1) Hatcher, Gordon H. Universal Free Health Care in Canada, 1947-77. 1981. U. W. Dept. of Health and Human Services.

(2) Canada, Statutes. 1957 Eliz. 2, Chapter 28, 5-6. Canada Hospital Insurance and Diagnostic Services Act.

(3) Canada, Statutes. 1976 Eliz. 2. Capter 107. An Act to Amend the Medical Care Act. (Bill C-68).

(4) Canada Health and Welfare. 1983. Cultural, Public and Information Programs Bureau, Ottawa, Canada.

(5) Charron, Monique. Long-Term Care Needs of Canada's Elderly, in ISSA Studies and Research 21:1984. Geneva

(6) Kane, R. A. and Kane, R. L. 1985. "The Feasibility of Universal Long-Term-Care Benefits: Ideas from Canada." New Engl. J. of Med. 312(21):1357-1364.

(7) Law Reform Commission of Canada. Consent to Medical Care. by Margaret A. Somerville. Ottawa. 1980.

(8) Gordon, Robert and Verdun-Jones, Simon N. 1983. "The Right to Refuse Treatment: Commonwealth Development and Issues." Internat'l. J. of Law & Psych. 6:57-73.

(9) Criminal Code, Section 45:
Every one is protected from criminal responsibility for performing a surgical operation upon any person for the benefit of that person if
a. the operation is performed with reasonable care and skill, and
b. it is reasonable to perform the operation, having regard to the state of health of the person at the time the operation is performed and to all the circumstances of the case.

(10) Criminal Code, Section 234.

(11) Criminal Code, Sections 465, 543, 608.2, 738(5), 738(6).

(12) Criminal Code, Section 545.

(13) Criminal Code, Section 546.

(14) Beausoleil v. La Communaute de Soeurs de la Charite de la Providence [1965] 13R. 37; Villemure v. l'Hopital Notre-Dame and Turcot [1973] S.C.R. 716.

(15) Law Reform Commission of Canada. Medical Treatment and Criminal Law. Working Paper No. 26. Ottawa. 1980

REFERENCES, continued

(16) Law Reform Commission of Canada. Euthanasia, Aiding Suicide and Cessation of Treatment. Working Paper No. 28. Ottawa. 1982.

(17) Laporte v. Laganiere (1972) 18C.R.N.S. 357 at 361 (QUE. Q.B.)

(18) Smith v. Aukland Hospital Board [1965] N.Z.L.R. 191 at 219; Mulloy v. Hop Sang [1935] 1W.W.R. 714.

(19) Culliton, Barbara J. "Helping the Dying Die: Two Harvard Hospitals Go Public with Policies" Science 193, 17 Sept. 1976, pp. 1105-6.

(20) Canadian Medical Association (1975):
(Art. 18) "An ethical physician will allow death to occur with dignity and comfort when death of the body appears to be inevitable;"

(21) By court order upon application in British Columbia and Alberta; by court order in Nova Scotia, Prince Edward Island, Newfoundland; by court order with provision for trial by jury in Ontario.Law Reform Commission of Canada. Sanctity of Life or Quality of Life. by Edw. W. Keyserlingk. Ottawa. 1979.

(22) Law Reform Commission of Canada. Sanctity of Life or Quality of Life. by Edward W. Keyserlingk. Ottawa. 1979.

(23) St.John-Stevas, Norman. The Right to Life, Holt, Rinehart and Winston, New York. 1964.

(24) Ramsey, Paul, "The Morality of Abortion," in John Rachels (ed.), Moral Problems: A Collection of Philosophical Essays, Harper & Row, NY 1971.

(25) Pope Pius XII, AAS 49 (1957) 1031-32.

LIFE SUSTAINING TECHNOLOGIES AND THE ELDERLY

LEGAL ISSUES

YUGOSLAVIA

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FINANCING OF HEALTH CARE

Different laws exist on the Federal, republic and provincial levels with regard to health insurance for about 98% of the population. The health insurance system is based on the principle of solidarity and is compulsory in character. The costs for health services are usually covered from the funds generated from contributions for health insurance, from governmental expenditures and other public revenues (1). All who are not covered by the health insurance, e.g., the poor and groups without income, are entitled to all medical services at the public expense.

In addition some health services are offered free of charge for everyone, e.g. mental disorders or malignant illnesses. Furthermore, some medical services have to be paid in part by the patient. Especially prosthetic dentistry, medical services of aesthetic character and treatments in spas and health resorts. In some cases also rehabilitation, except if this is necessary as a follow-up of hospital treatment. Usually it is up to the individual health insurance system to decide on the coverage in accordance with relevant regulations but all patients suffering from chronic diseases are exempt from their part of the cost of medical treatment necessary.

The health care system is financed from the following sources:

- personal income contributions of workers, farmers and other groups covered by compulsory health insurance

- enterprise income contributions and those of other organizations/institutions, e.g. health care/health protection for workers

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- governmental expenditures especially for health care of temporarily unemployed and low income groups and partial coverage of health care expenses incurred in underdeveloped regions (2).

Methods of Payment

Users of health care allocate and pool resources for financing of health institutions according to the health care program. These are jointly adopted by health workers and users annually basis and serve as a basis for setting the price of health services. Within these programs, health institutions, users of their services and self-management comunities of interest determine type and scope of health services, prices for the health services as well as other regulations significant for the implementation of the health care program. Health institutions and patients together decide on the cost of health services and how they are covered. The income of health institutions is generated in several ways: flat-rate payment; per inpatient, according to the type of illness; per unit of health service. The salaries of health professionals and health workers are regulated by every health institution and are based on guideline salaries according to performance (3). In general the system of financing is structured to ensure equality of socioeconomic status of health workers and those employed in other organizations of associated labor.

Patients Rights

According to the Constitution of the Socialist Federal Republic of Yugoslavia, everyone has the right to health care as well as to a healthy environment (2).

These basic rights are specified in detail by numerous laws and regulations, passed in all the republics and autonomous provinces. The rights of patients are stipulated in regulations on health care and health insurance schemes. Even the right to health services of high standard is not explicitly specified, especially due to the still limited territorial accessibility of health services in certain underdeveloped regions. It is understood that medical institutions which offer such services have taken all legal and professional measures to ensure services of high standard offered to patients.

In addition to the basic right to health services, the patients have the right to

- financial benefits while on sick leave,
- examination by a council of specialists,
- medical record-keeping in secret,
- personal or immediate family consent for surgery,
- objection to poor quality of service or treatment,
- to be treated abroad in competent institutions if adequate treatment is not available in Yugoslavia itself (3).

The patient may protect their rights and interests on the basis of the law on health care in civil or penal procedure.

Special programs for the elderly

There are programs for the elderly with so-called "gerontological ambulatories" which are a combination of educational and clinical institutions where long term care is also provided (1). Especially war veterans, disabled veterans and other disabled persons and those over 65 years of age have the right to

periodical thorough examinations for prevention.

Recent laws regarding the health care system:

- Law on the system of social planning and the social plan of Yugoslavia (1978),

- Constitution of Yugoslavia from 1974 introduced a new mode of self-management in the health field (3).

Organizational and legal aspects

The Constitution of Yugoslavia from 1974 introduced a new mode of self-management in the health field as in other social activities:

Self-management organizations of the insured citizens have evolved parallel to health legislation and social insurance. The main purpose is to enable the insured to exert their direct influence on the management of funds allocated to health services and to exercise other rights within healthy retirement and disability insurance schemes (3). For this the users of health services (insured) and the providers (medical staff) establish self-management communities of interest for health care in which they determine the direction of the development of health services and health care including health promotion. There are also self-management communities of interest for retirement and disability insurance.

The insured pool resources, define rights and obligations and realize their common interests on the basis of reciprocity and solidarity. These self-management communities of interest for

health care have constitutional rights in collective decision-making and deciding on the matters related to the health field together with competent government bodies as equal partners.

The long run strategy is to further develop this system of collective rights and decision-making on a number of other health issues which are under the jurisdiction of government bodies so that the function of the state is gradually narrowed and reduced to the social supervision and surveillance of the self-management communities of interest. This major change strengthened the role of the communities and provinces in the health field. Every republic and autonomous province regulates organization of health activities and implementation of health care services on its own; no development planning or programming takes place on the federal level. But in case there is a need to do so, there are no legal obstacles. There is a strong tendency towards association on one side and division of labor on the other side among specialized health institutions to ensure high standard of health services.

There are no privately owned health institutions and they may be established only by legal persons.

Regulations on social insurance and legal provisions on labor and employment have a strong and significant impact on the offered health services, since these regulations

- proclaimed a widespread health and social welfare of workers
- ensured their rights to health protection, treatment and rehabilitation

Regulation of health care systems:

As mentioned, the legal responsibility and the legislative power in the health field falls within the competence of republics and autonomous provinces and partly communies.

The federation retained only the power to regulate some issues of significance for the entire country and the international community, e.g.

- prevention of contagious diseases
- production and marketing of narcotics
- health certificates for food
- health protection for foreigners
- environmental protection and
- rights rising from retirement and disability insurance.(3)

On the federal as well as on the provincial level committees for labor, health and social welfare work closely together via numerous forms of working groups. The republics and provinces are responsible for the implementation of the federal regulation represented by the federal committee for labor, health and social welfare.

Most laws passed in the field of health legislation serve mainly as guidelines and contain usually only the goals to be attained but leave the means and ways to the competent administrative bodies or health institutions or other agents determined by law on the federal, republican or provincial level.

All laws on various levels prescribe fines for violation of certain provisions or offences against regulations such as those listed below:

- unconscientious treatment of the patient,
- refusal to attend the patient,
- practicing "quack" medicine,
- careless behavior in preparing and prescribing medicines.

In the annual development plan of health activities and health care adopted by the self-management communities of interest for health care the types and scope of health services, priorities and other issues of importance for the health promotion and funding for each region are specified.

To ensure proper implementation and operation, a system of control was developed. Internal control is carried out within every health institution by managers and other experts. External control includes supervision of professional work, supervision of legality of work, sanitary supervision, and supervision over the use of social funds. This is carried out by competent government bodies via special commissions of experts in accordance with procedures prescribed by republican and provincial laws on health.

The legal responsibility of health workers is determined by regulations in the health field as well as in penal legislation under specific headings dealing with criminal acts against human health.

In general the number of punished workers is low and there is no upward tendency. There is also a code of ethics which binds all medical and health workers regardless of title and position in the profession under health care laws. These laws prescribe all health workers to offer health protection according to contemporary scientific achievements and knowledge, respecting the patient's personality and safeguarding professional secrets.(3)

Violation of these professional responsibilities are is prosecuted on several levels:

- discipline commissions in health institutions,
- special courts of associated labor (in case of appeals),
- honor courts within associations of health workers (3).

It should also be noted that private medical practice is prohibited in Yugoslavia for all health workers. The last exceptions in one of the republics came to an end in March, 1985. Therefore health institutions are independent self-management organizations of associated labor in which medical and other health workers are employed.

Medical Ethics

There are no specific government bodies concerned with medical ethics, but the ethical questions related to death and dying are increasingly debated. Therefore, the Yugoslavian government is working strongly for a legal base of the use of life-sustaining technologies and treatment decisions. One proposal discussed is that a commission of family members, physicians and lawyers should decide but this is still in progress. (1)

In general, universities play a leading role in the development of medical ethics, and five academic groups are currently involved in research concerning the quality of life. Several medical institutions have begun courses on death and dying. In addition two symposia on medical ethics were held on the subjects of "Medical Ethics in Education" and "Rights and Responsibility of the Patient." Furthermore, there is a growing understanding in Yugoslavia to participate in the discussion on medical ethical issues at the international level. For that, the

Yugoslav Center for Medical Ethics and the Quality of Life sponsored an international conference at the Inter-University Center in Dubrovnik in June of 1984.(7)

Foregoing Treatment

Every patient has a right to refuse treatment as well as to be treated in a proper way, but the law only guarantees the universal right to treatment and health care. Overall there are few old terminally ill patients who commit suicide (or attempt it) and if they do, they are put into a mental hospital. "I do not know of any case when elderly patients refused treatment" (2). They usually all want to live and survive no matter how sick and old they might be (4). If somebody expresses the wish to die, it is usually seen as a temporary thing or as a result of depression and treatment is always continued. In a severe case, the patient would be transferred to a psychiatric hospital (5,6).

But if a patient is fully conscious and refuses any treatment, the physician won't interfere. "I know of one case when the patient refused all treatments and insisted to die at home. He was sent home and died there without further interference by the physician" (4). However usually the physician tries to persuade the patient who refuses treatment or wants to go home, so that he will stay. There are very few of such patients. (4) "We only know of one terminally ill patient who tried to commit suicide. These cases are very rare" (5,6). In general, suicide is not allowed or accepted as a "proper" solution. Neither providing means or passive assistance in suicidal actions nor active help is allowed for the physician or any other caregiver (4).

INCOMPETENCE

In case the patient is incompetent (unconscious or has a guardian) to decide for himself, the decision will be made by the physician in accordance with family members and relatives (2,4,5,6). If a patient seems to be mentally disturbed, he will be observed over a longer period of time until a decision is made as to whether he is able to anticipate the consequences of his actions (4,5). The assessment of disturbance is usually based on a "common sense judgment" and not scientifically tested (4). If the patient has lost consciousness the physician usually consults and informs the family, and then decides on further action. Family members as well as other care givers are not in a strong position to influence the decision however. Also guardians are rarely involved in the decision making process (4).

Living wills or other advance directives do not exist and there are rarely problems with the decision making process in case of incompetence, e.g. courts are never involved (2). There have been some cases of expression of advance directives, but the final decision depends on the physician with regard to diagnosis, chances of survival and availability of further treatment (4,5). The matter was also already discussed on public television (5,6). It seems that the situation in homes for the elderly is more "humane" than in hospitals, since the physician can decide not to send the patient to an intensive care unit of the hospital, but to let him "die with dignity" in his environment if he has expressed that wish (5,6). Sometimes if the family members insist on taking the patient home, even if he is in critical condition, but has a 5 to

10% chance of recovery, the physician would try to persuade the family to leave him in the hospital or to take him home on their own responsibility (4).

Overall it can be said that the patient has an "unwritten" right to die as long as he can decide for himself and as long as he expresses that wish seriously. The same situation is possible with the members of the Jehova's Witnesses. If they present a written statement that they will not accept blood transfusions, this will be accepted. However in case of emergency and without such statement it would not be accepted (4).

Liability for Decisions

There are no cases in Yugoslavia when the government prosecuted a physician for homicide (2,4,5) and only in very few cases courts were involved in law suits against physicians in general. In most of these cases when patients or family members sue their physician for malpractice, it was because of wrong or inappropriate treatment, but never because of <u>omitted treatment</u> (4). The new law will also help to clarify situations like that (2). "I only know of one case within the last two years when a physician was sued for malpractice, but the court decided that the treatment he gave was correct" (2). One reason for rare law suits might be the fact that patients as well as family members can not sue their physician for money, but only for punishment of the offender (e.g., the physician loses his license) (2,4). Ultimately the physician takes the responsibility for treatment decisions. Unlike in other countries, nurses have considerable responsibility for patient care but if something goes wrong, it is the physician

or the hospital which is liable. Ethics committees are established in hospitals and they regulate the selection of patients for organ transplantation, but in general, their main task is to serve as a commission for research projects (2,4).

Influence of religion

Muslims (in the south) and Christians (in the north) are the two main religious groups in Yugoslavia. A small group of Jehovah's Witnesses is also found. With regard to that matter, religion has no direct influence beyond the general value statements of the church but there has not been any official statement by any of these groups (2,4,5).

Technical Issues Related to the Critically or Terminally Ill Elderly

Dialysis as well as kidney transplants are covered by the health insurance system, and there are enough machines available for everybody who needs them (2). However, some areas are not as highly developed as Slovenia (4).

Kidney transplants are relatively rare and until recently patients were sent abroad for the operation. In 1986 a donor system was introduced which allows the removal of organs from dead people, rather than relying solely on live donors (usually relatives of the patient) (5). All physicians agreed that age is an important factor in allocation of kidney transplants, but it is not a deciding one. More for medical reasons, the age limit for transplantation is about 60-65 years.

Home dialysis machines are very rare. In Slovenia there are only two machines available. Right now also no specific interest or priority exists to make them more popular (6). The treatment of endstage renal disease has generated heated debates since 1974 when chronic hemodialysis was introduced on a limited basis. (7)

Nutritional Support and Hydration are considered as minimum and very basic treatment. It is not permitted to withdraw them in any case, but there is no specific legal base for this. Especially since the physician is also not obliged to continue maximum treatment. Theoretically the physician could decide to withdraw nutritional support and hydration, but it is almost never done. As long as there is no legal regulation, it is still with the physician that the decision rests (4). Elderly as well as young patients are treated the same according to their needs. Withholding treatment is not a common practice.

Resuscitation. Written DNR orders are not used in the hospital (2,4,5,6). Nursing homes usually do not have the equipment to resuscitate although heart massage is performed (5,6). In some cases resuscitation is not likely to be applied, e.g. metastatic cancer patients (2,4,5,6), cardiac patients with several rehospitalizations (4).

Age is not considered a deciding factor, instead the diagnosis and the general condition of the patient is more important (2,4,5,6). If the physician knows a patient and his history very well, and he and his colleagues agree that resuscitation is not

appropriate anymore, an R is sometimes marked on the patient's chart (4). But if the physician does not know the patient, resuscitation is always performed even if the patient is very old (4). Elderly patients are commonly resuscitated (4,5,6), and in general it is recognized that more technical difficulties are involved (5,6). Failure to resuscitate does not lead to civil or criminal proceedings since family members rarely question the physician's decision (2,4,5,6). But since the family members have the right to sue for malpractice, it may be that in the future family members will become more sensitive and aware of that possibility (4). On the other side, it is more likely to be criticized by colleges (4).

Ventilation: Mechanical ventilation is widely available in hospitals, but not in nursing or private homes (2,4,5,6). It is done primarily in intensive care units and one center in Slovenia specializes in long term ventilation of patients with neurological or severe internal diseases (2,4,5,6). Some of these patients are ventilated for 2 to 3 years (5,6). Once applied, ventilation is never withdrawn and usually it is easier to withhold it in the first place which is decided by a team of physicians (4).

Financial aspects never influence the decision only the medical needs of the patient (4,5,6). One reason for that might be that there is not a high demand for ventilation machines anyway (4).

Antibiotics: All physicians agreed that infections are a common cause of mortality and that in general terminally ill elderly are treated as aggressively as other patients (2,4,5,6). If they are treated less or with smaller doses, it is always due to their limited renal function (4).

Differences in the use of antibiotics can be found on several levels. There are differences between hospitals and homes for the elderly in so far as different levels of training and knowledge of the physicians have to be taken into account as well as the greater variety of antibiotics available in hospitals (4,5,6). On the other hand, general physicians seem to prescribe antibiotics much more frequently than hospitals which might be due to the reasons mentioned above (4). Doctors do not profit from giving prescriptions (4,5,6) but it is relatively frequent that they are pressured by their patients to prescribe antibiotics. Not infrequently, the drug the patient asks for will be prescribed, if it can be justified, even though it may be the less appropriate choice (4).

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REFERENCES

(1) Ivan Pusnik, vice consul in Munich,

(2) Dr. Dinko Leskovsek, President Deputy, Republic Committee for Health & Social Welfare, Ljubljana,

(3) Georgievski, N. and Udovicic, B. "Trends in Health Legislation in Yugoslavia," in Health Legislation in Europe, WHO Regional Office for Europe, Copenhagen, 1984.

(4) Doc. Dr. Dusan Kleber, Director of the Slovenian Institute for Gerontology, Ljubljana,

(5) Dr. Cec Alenka, Institute for Gerontology, Ljubljana,

(6) Dr. Vincenc Logar, General physician at a home for the elderly, Ljubljana.

(7) Lang, S., Woolhandler, St., Bantic, Z. and Himmelstein, D. U. "Yugoslavia: Equity and Imported Ethical Dilemmas" in The Hastings Center Report, December, 1984.

LIFE SUSTAINING TECHNOLOGIES AND THE ELDERLY

LEGAL ISSUES

FEDERAL REPUBLIC OF GERMANY

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FINANCING OF HEALTHCARE

The Federal Republic of Germany is a federal state consisting of 10 "Laender" which have their own national status and their own legislative powers but are integrated into the Federal Republic as a whole. They also participate in Federal legislation in the "Bundesrat" in which all minister-presidents are represented. Therefore, the Laender implement not only their own laws but also Federal laws; especially the field of health and social legislation typifies this Federal state principle. At both Federal and Laender levels authority is divided among various ministries.

HEALTH AUTHORITIES

At the Federal level the Ministry of Youth, Family Affairs and Health has a strong but limited influence on health care questions. It is important to know that the Federal Republic has no general legislative power in the health field. Federal control exists on:

-control of infectious disease
-disease of public danger
-health profession standards
-public welfare
-hospital finance
-social insurance & labor protection

The Ministry of Labour and Social Affairs as well as the Ministry of the Interior and the Ministry of Research and Technology are also involved in these control processes.

In all other areas the responsibility for legislation lies with the Laender governments with a strong network of coordination

guaranteed by several institutionalized working groups;

-conference of the health ministers

-working groups of medical administrators

-working groups of the Federal Health Board and the health boards of the Laender.

There is a basic "Right to Health Care" since the health care system is a part of the compulsory general social security system, which consists of the:

-Health Insurance System

-Accident Insurance System (including rehabilitation)

-Retirement Insurance System

-Unemployment Insurance System

Participation in each of these benefit systems is obligatory for everybody.

Only high income employees and self-employed are exempted from this compulsory insurance. The financing is guaranteed by a social security insurance and a state supported maintenance and welfare program.

Employee and employer share in the payments of health insurance, retirement insurance and unemployment insurance. Only accident insurance payments are met by the employer alone.

Wage earners are subject to compulsory insurance regardless of their income. Only salaried employees can take advantage of the exemption. Civil servants are exempted from compulsory insurance, but the regulation gives them the possibility of voluntarily joining a scheme. Pensioners are universally insured. Their contributions are met mainly by the old age insurance scheme. The 1982 pension

amendment law removed pensioners' obligation to contribute based on allowances received in addition to their pension.

The financing of the health care delivery system rests on various bodies:

- the State
- the statutory health insurance system
- the private health insurance scheme
- other systems (social assistance and welfare)

One third of the social expenditure is met from the public funds from the Federal Republic and the Laender, the rest by contributions from insured persons and employees. Almost 40% of the state's social budget is spent on the care of the elderly and dependents of the insured. The statutory health insurance system covers over 90% of the population, 8% of the population has complete insurance coverage outside the statutory system -- predominantly under private insurance schemes. It consists of about 1900 semiautonomous sick funds (Krankenversicherung) under the general supervision of the Ministry of Youth, Family Affairs and Health.

The assessment of an individual's contribution to the sick fund is based neither on his physical condition nor on his age; neither on the size of his family nor on the number of family members who will be covered by the insurance. It is based solely on his income. Every insured member pays the same percentage of his gross monthly income up to a maximum income level. This percentage is determined by the health insurance funds in accordance with their own financial situation (within a framework of legal restrictions).

Thus, though the percentage is the same for everyone, people who earn more, actually pay more.

Those who are privately insured are covered by a different reimbursement policy than the statutory health insured people. They usually are billed first and then get reimbursed 100% later. The regular health insurance is guided by the principle of "payment in kind", which means that insured persons and their families receive medical services, drugs, hospital care etc. without payment or for a nominal charge (e.g. 2 DM per prescribed drug) under arrangements agreed upon between health insurance authorities and the providers of services (physicians, hospitals etc.). Dependents and senior citizens are exempt from payment.

Individuals with no personal income, insurance pension, or alimony receive health care benefits under the provisions of the federal law on social welfare. Handicapped people (e.g. those disabled at birth or incapable of earning a living) receive vocational rehabilitation under old age and accident insurance or from the Department of Labor to help them reintegrate into society, in addition to health benefits from sickness, old age and accidental insurance.

The funding of the health care system is broken down as follows:

	DM Billion
Government Funds	28.6
Statutory Health Insurance	87.5
Private Health Insurance	8.8
Pension Insurance	14.8

Statutory Accident Insurance	6.3
Employers	37.8
Private Funds	16.7
TOTAL	200.5 (billion Marks)

LEGAL PRINCIPLES IN LEGISLATION

Basic to current health and social security systems is the 1949 provision in the German Constitution (Grundgesetz (GG), Article 20) which emphasizes the high priority of the "Social State" concept and which commits the government to the social security and social welfare of its citizens.

In addition, health insurance is the oldest part of the social security system dating back to Bismarck's government in 1883, with the main principle still incorporated in the legislation today.

Other important laws since 1972 include:

-Law on hospital finance (1972)

-Law on the further development of health insurance (1976)

-Law on the containment of health insurance costs (1977)

-Reform of laws on medicaments and on rehabilitation (1974)

-Law on the severely disabled (1974)

SPECIAL GROUPS AND SPECIAL HEALTH PROBLEMS

No comprehensive surveys of the health status of the whole population have been conducted. Only a system of spot checks (micro census) provides data. There is no comprehensive national health plan nor are there comprehensive plans in the Laender. Special programs are drawn up according to need in individual problem areas. Among the special services and programs there is the emergency and

relief service which has a 24 hour emergency service and a health care service of the elderly. Elderly people are helped to maintain their independence for as long as possible, and residents of homes are helped to maintain their ability to take an active part in the life of the community.

In addition there has been a continuous expansion of

-nursing homes for the elderly

-nursing homes for the disabled

-old people's homes with or without nursing care

-psychiatric and neurological clinics

-geriatric hospitals

-hospitals for the chronically ill

-social service centers

The latter are promoted by local communities and Laender and provide outpatient care for the sick and elderly. Today one social service centre is considered essential for approximately 28,000 citizens.(2)

It seems quite justified to put the elderly and the disabled together in one problem group (2).

The need for basic nursing assistance for the elderly and disabled has increased within the last 20 years. According to the report of a joint Federal/Laender working group on the "structure and financing of community and institutional care" (Aufbau und Finanzierung ambulanter und stationaerer Pflegedienste) (2) there are 5.5 million disabled persons with "identity card for the severely disabled" (Schwerbehindertenausweis); 34.9% of these are over 65

years old. The Federal Statistical Office data for the period 1974 to 1980 (Microcensus data) on chronically ill persons show 9 million or 11-15% of the total population belonging to this group; of which 85% are age 65 and older. A 1975 survey on people on domiciliary care and treatment showed that 1.5 million or approximately 3% of the total population are homebound with 75-80% over age 65 and older. 250,000 of them received care in an institution (nursing home for the elderly, old peoples home, hospitals for chronically sick, nursing homes for disabled etc.)

These facts cause a tremendous problem for the social security system:

1. Since sickness and old age insurance do not cover long term needs; the social welfare and the social assistance system has to cover all basic needs, necessary treatments and care. This "right to health care" is in addition to the articles in the constitution (Grundgesetz) backed up by the social legislation code (Sozialgesetzbuch), paragraph 10, which states that "all those suffering or likely to suffer from physical, mental or psychological disability have the right to all necessary assistance in order to prevent further deterioration and reduce its consequences" (2).

2. Of those being cared for in institutions, 90% are not able (regardless of the amount of their pension) to pay for the necessary expenses and are dependent on financial support through the social assistance and welfare system. In addition 50-80% of the cost of all long-term care patients is currently met through social assistance and welfare support, which adds

to 5.000 million DM (ca. 2 billion $US) per annum expenditure on social assistance and welfare which has to be paid mainly by the communes and Laender (2).

The Federal Government as well as several Laender have introduced different programs to mitigate these problems.

Having in mind that the proportion of the elderly will increase and in addition the proportion of disabled and people in need for long-term care, the Federal Government introduced the "First Action Program" in 1970 and a "Second Action Program in 1981 (the International Year of Disabled Persons) with the following orientation and goals:

-activities for the prevention of disability and

-activities for the care of the disabled, with a major focus on rehabilitation.

On the Laender and local level, programs followed along the same slogan: "Rehabilitation rather than pensions". Social service centers providing outpatient care for the sick and elderly have increased rapidly.

Although care requirements and the corresponding financing for institutions responsible for providing available treatment are almost always met, there are still important shortcomings, particularly with regard to nursing care for the disabled and elderly. The Federal Government therefore introduced a comprehensive "model program" under which model establishments will be created to provide general psycho-social care combined with nursing services and at the same time collaborating with doctors responsible for primary care (2).

A Federal/Laender working group which was given the task of analyzing the problem of the creation and financing of community and institutional care recommended a change in old age and sickness insurance as well as introduction of special insurance to cover long-term care based on the principle of solidarity, which should cover institutional and community care. The estimated total expenditure required is in the range 14.000 to 20.000 million DM per year.

Until now no solution has been found for the problem of finance and the problematic distinction between chronic ill patients and patients who "only" need care remains: e.g. if a patient is diagnosed as sick, sickness insurance covers 100% of the cost incurred. But if the diagnosis is only that care is required then only the cost of care would be covered, which in the case of placement in an institution would be only 25-30% of the total expenditure. The rest would have to be covered by the insured patients themselves (savings, pension etc.) or their family members (children or partner). If there is no sufficient financial sources available, social welfare assistance will cover all costs. In addition, expenses for care are tax deductible. In case of unsuitable domestic environment the social assistance gives support to improve accomodations which are ill-suited to the needs of those being cared for and to provide for nursing requirements (if patient is eligible for social welfare support.)

FOREGOING TREATMENT

Every patient has the right to forego treatment as long as he or she is considered conscious and aware of the consequences of his/her decision. Article 2/II 1 GG (Grundgesetz) of the constitution guarantees every German citizen the right for personal integrity (Selbstbestimmung) and privacy protection (Unversehrtheit der Person). Physicians are usually (except in emergency situations) not allowed to treat a person without formal consent. Otherwise it is considered as bodily injury (223 STGB) and can be prosecuted. A major limitation to forego treatment is whether the person is under age or is not considered competent and whether a guardian exists. If a patient is without a guardian and considered not competent the physician has a limited right to decide on the treatment for the patient, following the medical principle and ethics of keeping the patient alive (13 STGB). The physician has the obligation to do whatever is possible for the good of his patient. He has a "guarantee" contract as he accepts the person as a patient.

If a person refuses to eat or refuses to take a medication usually there will be no interference if he is fully aware of what he is doing. However as soon as he loses consciousness one is obliged to help in an emergency case (330 c STGB). An action would be considered suicide if the patient killed himself in an active way (e.g. poisons himself, shoots himself, strangles himself, etc.)

If suicide were attempted the physician and everybody else is usually obliged to help, otherwise, he might be accused of "withholding help" (323 c STGB). Basically there is only one

exception. Physicians can withhold treatment from a person who tried to commit suicide and is about to die when the physician discovers that the trauma to the person is irreversible and the use of intensive life support care would therefore be not justifiable with regard to the person's further life. As an example cited is the case of Dr. Wittig-Charlotte Uhrmacher (see Appendix I).

Usually, if a patient commits suicide it is necessary to report it to the police for further investigation. For a legal backup of these "suicidal actions" and for protection against the application of life sustaining technologies a document called "Patienten Testament" (living will) was introduced in 1978 by UHLENBRUCK. He is considered the pioneer in this field. Since 1980 there is also a "Deutsche Gesellschaft fuer humanes Sterben e.V." (German Society for Dying with Dignity) which demands the right to die with dignity. This society established UHLENBRUCK'S idea and distributes a brochure which is called "Menschenwuerdiges und selbstverantwortliches Sterben" (dying with dignity and self-responsibility). This brochure gives advice on how to commit suicide safely. It also provides legal support for all members electing to foregoing treatment, or to avoid unwanted treatment after loss of consciousness. It also provides declaration forms to express living wills (Patiententestament/Patientenbrief).

As some authors and medical law specialists mention there may be legal problems with regard to the power of attorneys. The living will might lose its power as soon as the patient loses consciousness. (3)

There is neither a statutory law nor a principal decision from the highest criminal court (Bundesgerichtshof) available for a final solution.

Until now there was also only one case when the "German Society for Dying with Dignity" had to interfere to prove a patient's right (4).

In other cases like when the patient tries to kill himself by not taking medication or refusing to eat, it is usually assumed, that he is not fully aware of the consequences, therefore the patient will be treated according to his medical needs. In some cases guardians with limited deciding power (only with regard to health and treatment aspects) will be provided. For that it is necessary that the physician and the court decide together on who should be the guardian (mostly a close family member). This process is called "Pflegschaft zur Heilsversorgung". In such cases the physician's treatment decision has to be approved by this guardian.

INCOMPETENCE

When a patient is not competent, meaning, that he is either under age or unconscious or is not able to judge the consequences of his decision (e.g. patient has a guardian which has to be determined by a court), the physician has the full responsibility to make decisions for the patient. Legally it is not necessary to consult family members for decision making but usually physicians do get in touch with them and discuss the situation, as long as it is not an emergency. The physician is obliged to do the best he can for the

health of his patients (813 STGB). Furthermore the physician has to decide on the treatment procedure with regard to the "presumable will" of the patient (5). There are provisions for living wills (Patiententestament) but especially when the patient has lost consciousness the statement is considered without legal power, even though in practice it can be a helpful "hint".

Surrogate decisions are often made on the basis of the diagnosis. GROOS and TAUBER (3) mention that the following criteria for withholding treatment are used or should be used:

-hopeless prognosis

-final stage of disease

-inoperability

-no effective therapy known

-progressive suffering

-to the best of the physician's knowledge-death would be only a matter of time.

Similar criteria are suggested by the Deutsche Gesellschaft fuer Chirurgie" (6), which developed its guideline from that of the Swiss Academy for Medical Sciences published in 1976 (Richtlinien fuer die Sterbehilfe/Guidelines for Dying with Dignity). The document states that if a patient is deadly sick and incompetent to express his will (e.g. unconscious) it is the duty of the physician to act on behalf of the patient's presumable will ("Geschaeftsfuehrung ohne Auftrag"). In this case the physician has to consider whether treatment may be the extension of pain and suffering.

In case the patient has expressed his living will or has given other written advance directives regarding the use of life sustaining

technologies, this fact can be taken as an important indicator, but the decision should ultimately be made according to his presumable present will, which can only be assessed by considering all aspects of the individual case. The guidelines mention that it can not be assumed that advance directives always express the patient's present interest.

The influence of family members and close relatives (even close friends) is only secondary with regard to treatment decisions. The final legal right and responsiblity lies exclusively with the physician except if the patient is either under age or has a guardian; in this case the physician has to make his decision in agreement with the parents or the guardian.

The wish of family members, close relatives or friends can never be used as a legal base for treatment decision (7). According to the German criminal law it is highly controversial whether the withdrawal of an already started intensive therapy is considered legal. BOCKELMANN (8) argues that a withdrawal of a treatment which leads to a premature death has to be judged as a criminal act (Toetung durch Unterlassung 216 STGB, killing by withholding help). Other medical law specialists think that it is legal to withdraw a therapy if it can be recognized as an artificial life support extension of a dying person. (7) For jurisdiction purposes the condition of the patient is the deciding factor, never the wish of close family members or friends. This can lead to a situation in which the physician continues a treatment with life sustaining technologies with or without the expressed consent of family members and friends.

Whether or to what extent with regard to the condition of the patient the physician is obliged by law to continue a life support treatment depends mainly on the circumstances of the specific case and whether the therapeutic procedures are seen as "imputable" for the physician.

SCHEWE (7) emphasizes the legal concept of "imputation" as the deciding measure: the German criminal law recognizes that in spite of a criminal omission there is no duty for legal action if it can be imputed that the person (in this case the physician) has acted according to his regular duties. The imputability and the limits of the physicians duty for care can be determined with regard to

-condition of the patient
-kind and quantity of necessary treatment
-personal and technological equipment of the clinic
-balancing of priorities
-wish of close family members and friends.

These are only "legal guidelines" since neither the statutory law nor the case law (except BGH judgement 1984) provides clear statements for such situations (7). The practice follows similar guidelines (9).

The role of caregivers in decision making for the patient is very limited, since the physician carries all the responsibility for the treatment and other decisions. Usually the physician is responsible not only for his own decisions but for the consequences of any actions of a caregiver under his supervision. (611/ 278/ BGB/civil law STGB/criminal law/bodily injury and killing due to gross negligence). On the other hand all caregivers, if they are

part of a team are responsible for their own actions (principle of self responsibility; 823/840 BGB)

No evidence could be found that courts are ever involved in decision making processes with regard to incompetent elderly patients, since it is daily practice and determined legally that the physician acts on the patients behalf as soon as he is incompetent.

In Germany as well as in the United States ethics committees (Ethik-Kommitees) exist, but their functions might be different. In Germany these committees almost exclusively deal with ethical consideration of medical research but do not influence decisions on the treatment of single patients. In the hospital, the Chairmen of the Departments involved usually get together and make the final decisions for the individual case (9,10).

LIABILITY FOR DECISIONS

In addition to what is mentioned earlier there are some other important factors to look at: most authors agree that the freedom of decision making among physicians is relatively high (11,12). The main responsibility lies with the Chairman of the Department or the attendant, other caregivers do not have great influence. One major factor regarding treatment decisions is the "quality of life" of the patient, e.g. his situation before and his hypothetical situation afterwards (chance or no chance to recover). For example, in case a patient refuses to eat, the physician is allowed to take action for artificial nutritional support, but he is not obliged to do it as long as the person is conscious and responsible. In rare situations this can also include the use of physical force (11).

With regard to the use of life sustaining technologies, the physicians are the final deciding persons with a high legal protection, but the fear of being accused for malpractice is growing. This protection goes as far as assisting someone or advising someone to commit suicide without having to face legal consequences. However active euthanasia, which means killing on request or killing through active help, is considered a criminal act (216 STGB). It is not forbidden for a physician or anybody else to give advice or to provide material (e.g. poison, gun, etc.) with which the patient can commit suicide. The most striking case since the existence of the Federal Republic of Germany was the case of Mrs. Hermy Eckert and her physician Prof. J. Hackethal in 1984.

Prof. Hackethal, a well known fighter against the traditional medical practice and malpractice and the head of a private clinic in the south of Germany, was involved in a highly controversal disputed case of suicide of the 69 year old Hermy Eckert with final stage skin cancer. Hermy Eckert, a long term patient in his clinic, approached him for support to commit suicide. Despite the far advanced skin cancer and tremendous pain, neither her mind nor her basic body functions were afflicted. The cancer solely destroyed head and face. After 13 surgery sessions the physicians decided that they couldn't help her anymore. For reasons of legal backup and perhaps to revive the debate on life sustaining technologies and dying with dignity, Hackethal filmed all the stages from the decision to commit suicide to the final death and released it to the public TV stations, all with the prior consent of Hermy Eckert. He was also the one who provided the poison zyancali and who gave her instruction and advice,

he even stayed with her until her death and informed the police afterwards. For legal purposes he provided zyancali since he knew that this is one of the rare poisons where medical treatment or help even if tried is not possible. Of course the public reaction was one of controversy, but he was not prosecuted by the government. Only almost all his colleagues condemned his action as active euthanasia and as not ethical for their profession (13).

Another famous case, which happened in Switzerland, but had also strong impacts on Germany, was the case of Prof. Haemmerli from Zuerich in 1975. He was suspended from his clinic and imprisoned because he was accused of killing on purpose (vorsaetzliche Toetung), because he withdrew nutritional support from incurable sick people. He only maintained hydration support. Potentially the court could have sent him to jail for between 5 and 20 years. The court found him not to be guilty because of the specific circumstances of the situation (4,14).

In Germany it looks like that courts are hesitant to judge medical practice and decisions. Some indications are the fact that in 1984 the highest criminal court (BGH) decided on one case and didn't have any comparable case for the last 20 years (13). On the other hand the German criminal statistics show only 55 sentences due to killing on request and in none of these cases a physician was involved (14). Finally, as BOCKELMANN (8) mentions, there has been no sentencing of physicians due to actions which could have been considered active or passive euthanasia in Germany. Even when there is a legal right for family members and for other persons to sue for malpractice (1), people rarely take actions against their physicians,

even though organizations for patients' rights and protections are growing and there is a trend to increased law suits (Patienten-schutzbund und Gesellschaft fuer medizinisch-chirurgisch Geschaedigte e.V. (9). A major point of legal intervention occurs when physicians either forget to ask for permission before the treatment or they do not give all necessary information to the patient to be aware of the consequences of the treatment and therefore have violated their duty to give enough information (10). Every patient has a right to see his medical records.

INFLUENCE OF RELIGION

There are two major religious groups which have a long tradition in Germany and therefore have a very strong influence on the social cultural as well as the political level. The north of Germany is predominantly influenced by the Lutheran-Protestant church while the south, particularly Bavaria and Baden-Wuerttemberg, is the domain of the Roman Catholic church. There are 26,625,000 members of the Roman Catholic church and 25,701,000 Protestants (in 1982, 62,000,000 total population). According to the constitution (article 140 GG), the church has the right to claim a tax on the income of every member (9%). Since traditionally the community life is centered around the church, it has a strong influence on the value and belief system of a large proportion of the population. Especially their ministerial workers, clergymen, pastors and priests can be seen as opinion leaders in many ways. The German Bishop Conference (Catholic), many moral theologists, and leaders of the EKD (Lutheran Church of Germany) have participated in the discussion on

life sustaining technologies and euthanasia. One major position is that human beings principally have no right to commit suicide (15). But there is a consensus that it is not the duty of a physician to extend life artificially. As the German Bishop Conference (catholic) puts it "the right to die with dignity can mean that not all medical technologies have to be applied, if they might only extend painful dying" (8).

TECHNICAL ISSUES RELATED TO THE CRITICALLY AND TERMINALLY ILL

Sources:

1. Dr. Peters, Anesthesiologist, University Hospital, Dortmund, (c/o J H M Institutions)
2. Dr. Fetter, Neurologist, University Hospital Tuebingen (c/o JHMI)
3. Dr. Knoll, psychiatrist in private practice, Marktobersdorf
4. Dr. Neeser, attendant, Dept. of Anesthesiology, Zentralklinikum Augsburg
5. Dr. Behr, internist, intensive care unit, Zentralklinikum, Augsburg
6. Dr. Mueller, surgeon in private practice, Vincentinum Hospital Augsburg
7. Dr. Reinhard, cardiologist, intensive care unit, Klinikum Grosshadern, Muenchen
8. Dr. Verhorver, neurologist, intensive care unit, Klinikum Grosshadern, Muenchen

Dialysis

Dialysis and kidney transplants are covered by the health insurance system without limitation. Dialysis machines are available to everyone who needs them; outpatient centers as well as hospitals are very well equipped (4,5). Usually dialysis centers are widespread where the people who need them commute to and often it becomes an important part of their social life and social activities (2). In addition some private organizations support patients in need of dialysis machines and kidney transplants.

Home dialysis is rare but is steadily growing. One of the deciding factor is the interest of the patient, whether he wants to use such a machine or not (5).

Kidney transplantations are not a question of financing but mainly a question of availability. A shortage leads to a waiting and priority list; but patients who have a relative as a kidney donor will be treated immediately (3). Every hospital has its own priority list and the patients are placed on these lists according to their needs; again, age is not a deciding factor, more important are the future perspectives of the patients and his immunological status (5).

If two patients have the same medical need for a kidney transplant and they only differ in age, then it might be more likely, that the younger patient will be prefered (6). In general kidney transplantations are rarely done in patients older than 60 years. Overall the numbers of kidney transplants as well as the demand increased over the last few years. (1,4,5).

Nutritional Support as well as Hydration are seen differently from other life-sustaining technologies, they are seen as the "sine qua non" (5), because once applied they are never withdrawn until the patient either dies or gets well and independent again. It is not permitted to withdraw either of them, except when the patient is brain dead. (7,8) The elderly are treated in the same way as any other patient (1,2,4,5). There is a tendency, since nutritional support is seen as a key position of intensive care, to decide in advance about the applicability of it regarding the health status of the terminally ill elderly patient; it is more likely that nutritional support will not be started at all than that it will be withdrawn (1).

Resuscitation

Do not resuscitate orders are part of the practice in the hospitals but written orders are rare. The decision is made mostly on the basis of the diagnosis of the disease and on the chance for recovery. The policy does not seem to be the same in hospitals and nursing homes. One physician reports that in his hospital there are no cases in which patients are not resuscitated even if there might be a chance of brain damage. As long as the consequences are not predictable, every patient will be resuscitated (7). However the elderly are commonly resuscitated even when they could be considered "hopeless cases" (4).

On the other hand, due to the limited availability of appropriate equipment as well as physicians on duty, it is more likely that patients in nursing homes are not resuscitated as often as those in hospitals (6).

But age never seems to play an important role in terms of treatment. In general, elderly are more often resuscitated since there are more older people in the hospital. Age might sometimes play a role with regard to chances for recovery (1,2,4) but even more important is the "quality of life" aspect which takes many factors of the patient's life into consideration (4). Resuscitation is not likely to be done with patients having brain death, severe brain damage or terminal stage metastatic carcinoma (5). For their own legal protection, physicians tend to stay away from writing DNR orders on the patient's chart.

Failure to resuscitate is very unlikely to result in civil or criminal law suits, especially since it is very hard to prove it.

There are no legal orders regarding the duration of resuscitation trials (1,2,4) and criticism from colleagues is more likely than malpractice claims (4,5). However, if an emergency physician does not resuscitate in a setting outside the hospital, he could get into trouble (4).

Ventilation:

Short term mechanical ventilation is available in every medium size hospital, but only a few are equipped with machines for long term ventilation (5). In nursing and private homes such machines are not available on a broad base, but some nursing homes do have such equipment (6). Mechanical ventilation machines are part of the standard equipment in intensive and emergency care units. Financial aspects never play a role in the treatment decisions. Ventilation is almost exclusively done in intensive care units and sometimes even "hopeless cases" are still ventilated (6).

Among the few long term users (more than 30 days) are primarily patients with severe pneumonia, brain damage (with reduced pulmonary functioning) (5), polytrauma with lung injuries, septic patients (4), Guillain-Barre-Syndrome (2).

Antibiotics:

In general infections are a common source of mortality, but usually the prescription of antibiotics to the elderly is not different compared to any other patient. On the other hand in intensive care units infections are not a common source of mortality (5). The best medication is always used, dependant on the kidney and liver functions (5).

But differences among hospitals and other settings are likely with regard to dosage. General hospitals will use higher doses, given parenteral, and for a shorter period of time, while nursing homes administer orally and with a lower dose (4).

Although hospitals may treat in higher concentrations compared to other settings, it is likely that patients in the hospitals are more severe cases (6). In general there is a high use of antibiotics in all settings which sometimes can be due to the request from the patients (2) but the decisions for prescribing antibiotics does not lead to any financial profits for the physicians (4). Most physicians agreed that the pressure from the patients' side, does not necessarily lead to a more frequent use of antibiotics (1,3,4).

APPENDIX I

Case: Dr. Wittig-Charlotte Uhrmacher

In June, 1984 the highest criminal court of the Federal Republic of Germany decided on the following case which was called the "Krefelder Fall": (after more than 20 years since the last case of Euthanasia):

Dr. Wittig was found "not guilty" by a lower court (Krefelder Landgericht) with regard to the accused being responsible for the death of the 77 year old Charlotte Uhrmacher. He was accused of "killing on request by withholding help" (216 STGB).

Charlotte Uhrmacher was his patient for several years and after her husband died she mentioned several times that she wanted to "follow him." She was under treatment because of her heart problem and arthritis. One day when Dr. Wittig wanted to visit her at home nobody opened. With a second key he opened the door and found her "heavily poisoned but still alive." In her hands she held a picture of her husband (to whom she was married for more than 50 years). Next to her Dr. Wittig saw Nosphium-Ampuls and tablets and a note which said:

To my physician!

Please no hospital! Salvation! I want to my Peterle (her husband)!

In addition he found a living will (Patienten-Testament) in which she expressed that she was fully conscious of her actions and that she did not want any treatment with life sustaining machines! Dr. Wittig accepted her expressed will and did not call the ambulance but instead he called the neighbor and both stayed with Charlotte Uhrmacher until she died a few hours later.

The highest criminal court (Bundesgerichtshof) found him also "not guilty". The opinion was as follows:

"The physician is allowed to concede that in this case there was no legal obligation to keep this dying person alive. Actions to sustain life are not necessary just because they are possible. Not the efficiency of a medical instrument, but the respect with regard to the dignity of life and of human beings determine the limits of the medical duty for treatment (13)."

But the BGH also pointed out that the decision was based on the specific circumstances of this particular case. At the time, when Dr. Wittig found her, the woman was already irreversibly damaged by the poison intake; in other cases of suicide where the person's condition can be reversed the physician has to follow his duty to protect the person's life by helping as much as possible. The BGH emphasized the applicability of its decision solely to this case so as not to establish standards for other cases or to set a general precedent.

APPENDIX II

A 60 year old physician was suffering from metastatic stomach cancer. The carcinoma was inoperable. After the 10th day of hospitalization a lung embolus caused the collapse of the circulation. An emergency surgery kept the patient alive. Being conscious again the physician requested his colleague not to take action anymore in case of a new collapse. Two weeks after the lung operation a heart attack led to a cardiac arrest. Against the patient's will he was successfully resuscitated during 4 separate efforts in one night. In the meantime, brain damage was severe enough that the patient could not recover consciousness. For 3 weeks the patient was kept alive in an intensive care unit. Respiratory paralysis occured. Hospital staff tried to initiate mechanical ventilation which was not successful. So finally he died....due to a technical breakdown (13).

Case 2:

There are 200,000 brain and head damages per year which have to be treated in a hospital. 25,000 of them with severe brain damage. At least 170,000 of them are resuscitated but only 1/3 is successful, (13). Some physicians confess frankly that they commit active euthanasia e.g. Dr. Meyerhoff, "I think I have killed 30-40 patients with an overdose of opiates." (14).

SCHARA (14) A woman suffering from amyotropic lateral sclerosis with progressing paralysis had declared in an earlier stage of the disease that she refuses ventilation. Now, unable to move, fully conscious but unable to speak she is hooked to a ventilation machine and she is happy about it. The only fear she has is that somebody may switch off the machine.

REFERENCES

1. Health Legislation in Europe - Country profiles; WHO - Regional Office for Europe, Copenhagen

2. Oldiges F.J., Long-Term Care of the Elderly and Disabled in the Federal Republic of Germany, in ISSA Studies and Research 21: 1984, Geneva

3. Groos E. & Tauber R.: Grundlagen medizinischer Ethick - Versuch einer Standortbestimmung: in: Fortschritte der Medizin 103 (1985) 3 p. 67-69

4. Atrott, President of the German Society for Euthanasia, Augsberg, Interview December, 1985.

5. Schuchardt V., Biniek R., Heitmann R.: Grenzen neurologischer Intensivmedizin: in Anaest. intnsivther. Notfallmed. 19 (1984) p. 65070

6. Deutsche Gesellschaft fuer Chirurgie, Richtlinien fuer die Sterbehilfe, 1977

7. Schewe G., Rechtsmedizinisches Konzilium: Ist Therapie-Abbruch auf Wunsch der Angehoerigen vertretbar? in: Muenchner Medizinische Wochenschrift 121 (1979) Nr. 9 p. 306

8. Bockelmann P.: Verlaengertes Leben - verkuerztes Sterben: in: Wiener Medizinische Wochenschrift 126: 11/12(1976) 1-4

9. Dr. med. Juergen Peters, aenesthesiologist, Dortmund (interviewed at JHMI, December, 1985)

10. Dr. med. Michael Fetter, neurologist, Tuebingen (interviewed at JHMI, December, 1985).

11. Foerster H.: Im Dilemma zwischen Hungerstreik, Zwangsernaehrung und aerztlichem Auftrag; in: Fortschritte der Medizin 103 (1985) 12 p. 73-75

12. Schuchardt V., Biniek R., Heitmann R. (as mentioned)

13. Der Spiegel 18/1984 "Helfen Sie, ich kann so nicht weiterleben"

14. Der Spiegel 7/1975 "Sterbehilfe - der Tod als Freund" p. 36-60

15. Boeckle F., Humanitas in der Medizin, Deutsches Aerzteblatt 1980

THE MEDICAL CARE AND TREATMENT OF THE CRITICALLY-ILL ELDERLY IN CHINA: ISSUES AND LESSONS FOR AMERICAN POLICIES

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It is only change that is at work here.

- I Ching

The Chinese love jade. That strange lump of stone with its faintly muddy light, like the crystallized air of the centuries, melting dimly, dully back, deeper and deeper...[the Chinese] seem to find in its cloudiness the accumulated sediment of the long Chinese past, and we think how appropriate it is that the Chinese should admire that surface and that shadow.

- Tanizaki Junichiro,
In Praise of Shadows (1934)

PROLOGUE

Like the emphasis and prediction of its ancient and venerated book, the I Ching, China appears to be in the midst of great social and economic change, even transformation. For nearly a decade, Chinese leadership has undertaken and pursued a daring and often paradoxical "Four Modernizations" policy--a national effort to update the country's industry, agriculture, science and technology, and defense. The unabashed goal of this self-proclaimed "second revolution" is the reshaping of the world's most populous nation into a prosperous and technologically-sophisticated world power. What has caught the eye of the Western observer is not only the pace and zeal of the peaceful yet dramatic shape of events within this country, but also the way in which its goals are being pursued. Living under the dictates of Karl Marx since the 1949 revolution, led by Mao Tse-Tung, the new system emerging in China either ignores or defies many of the precepts most cherished by traditional Marxists. State ownership has begun to give way to private property, central planning to competitive markets, and political dictatorship to limited economic and cultural freedom (Iyer, 1985; Church, 1986).

Such a turnabout has affected all aspects of Chinese life, including its

health care delivery system. Such a turnabout also has affected its many population groups and subgroups, including its elderly. This paper focuses on the delivery of care to China's fastest growing age group—the elderly, and in particular to its critically-ill elderly. It emphasizes the utilization of life-sustaining technologies and several accompanying factors—economic and financial, legal, socio-cultural, and religious—that shape not only the delivery system itself, but also the decision to initiate and continue treatment of the country's critically-ill elderly.

While this discussion cannot and will not overlook the current social and economic forces of change, the importance of this recent cultural drama must be viewed in the larger context of Chinese tradition and continuity that stretch back over three to five millenia. There is little evidence, for example, that the new elements of market capitalism will completely replace the older Marxist approaches. Rather, the conscious policy directive is an attempt to combine or blend these two contrasting and often conflictual approaches. Likewise, the communist and Maoist-inspired elements of four decades have never fully replaced, but have more often blended with, the many disparate traditions of its pre-socialist past.

Kissinger (1986) has noted that such amalgams and balancing acts have been characteristic of the Chinese over time. Ideological shifts go hand in hand with the longest uninterrupted history of self-government. Its cultural uniqueness goes hand in hand with an extraordinary variety among its regions, which are physically separated by vast distances and daunting geographic obstacles. These ethnic and geographic realities have historically "generated an oscillation between a fear of anarchy leading to stifling centralization and a loosening of controls in danger of turning into regional separatism." Nevertheless, the Chinese have time and again managed to find a middle ground--an accumulated sediment of culture and

spirit. Kissinger has characterized it as a "rhythm" distinctly Chinese. The "oscillations" have been, perhaps, tempered by the age-old dictum to, in the words of the Chinese sage, "seek balance and harmony in all things" (Lao Tzu, n.d.).

Against this backdrop of change within continuity, this paper begins with a background discussion of China and its people. For purposes of the Office of Technology Assessment report, this discussion includes a special focus on the country's strong religious and philosophic tradition. The Chinese health care system is then briefly described. A discussion of Chinese customs and policies toward the aged follows, with an emphasis and review of a number of relevant factors that influence and affect the care of the country's critically-ill elderly. And while the Chinese experience is arguably unique in many ways, this fact need not preclude lessons and implications for policies relating to the care of America's critically-ill elderly. The paper concludes with a discussion of possible benefits for the corresponding American experience.

BACKGROUND

Demographic Characteristics

Situated in the eastern part of Asia, China covers an immense area of about 3.7 million square miles—just slightly larger than the United States. Population density, however, is four times greater in China than in the U.S.[1] In fact, China is the world's most populous nation, with slightly more than one billion citizens. The Chinese count 56 distinct ethnic nationalities among its populace, though approximately 93 percent

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1 Only seven countries in the world have populations of more than 100 million. China ranks first, and the U.S. ranks fourth (Fisher, 1985).

belong to the largest group, the Han nationality (MOPH, n.d.).

China is administratively divided into 22 provinces, 5 "autonomous regions" (minority populations such as Inner Mongolia and Tibet), and 3 municipalities (Beijing, Shanghai, and Tianjin) that report directly to the central government in Beijing. There are also about 2,700 counties, and about 55,000 people's communes. Provinces contain districts composed of counties and smaller cities (Summerfield, 1979).

Despite its large land area, China contains vast stretches of mountain and desert, with only a relatively small part being arable. China must feed approximately 20 percent of the world's population with only 8 percent of the world's cultivated land. China's population, furthermore, is most unevenly distributed. The vast majority of people live in eastern China, with its three great river basins. Western China, with its mountains and deserts, is exceedingly sparsely populated with less than 5 percent of the population. In addition, fully 80 percent of the Chinese people live in rural areas, an almost exact reverse of the population distribution in the United States.

Even within its borders, China is recognized as a developing nation economically. A gross national product of $300 per person in 1981 (as compared with $12,820 in the United States) places China in the bottom third of developing nations (World Bank Atlas, 1983; Hsaio, 1984). Both the urban-rural makeup of its population, and its limited economic capacities have strongly influenced China's policies toward health and medical care.

Chinese Religion[2]

The allure of its modernization and new economic policies aside, China

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2 This discussion of Chinese religion, unless otherwise noted, is based on discussions by Capra (1975) and Samagalsky and Buckley (1984).

also must be viewed as an ancient country. The influence of its history is nowhere more evident than in its rich religious and philosophic tradition that continues to permeate the many facets of its culture, including its health care. Chinese religion, like other aspects of Chinese culture, has developed over a period of more than 3000 years and has absorbed many influences. It has been characterized as a mixture of philosophy, tradition, and superstition, but in the main has been influenced by three great trends in human thinking: Taoism, Confucianism and Buddhism. In their pure forms, each of these is more a philosophy (or way of life) than a religion. Taoism and Confucianism are often seen as two complementary traditions that developed in ancient China to deal with the two kinds of knowledge: intuitive and rational, and represented by the Chinese archetypal pair yin and yang which form the very core of Chinese thought. At the same time, all three philosophies have been inextricably interwoven into the fabric of Chinese religious consciousness, and the "popular religion" of the Chinese is best viewed as a fusion of ancient superstition with the three philosophies. The founders of these philosophies have all been deified and the Chinese have worshipped both the founders and their disciples. The people also have come to worship their own ancestors and a multiplicity of gods and spirits.

Despite the blurring of distinctions between the three philosophies in popular culture, it is useful here to briefly isolate the separate strands. Individually, each came to occupy a needed philosophic space. Taoism taught man to maintain harmony with the universe, not to disturb it. Confucianism, on the other hand, attended to the more practical political and moral aspects of life, and Buddhism took care of the afterlife.

Taoism. The concept of Tao itself is the center of Taoism. Tao is the way of ultimate reality, the basic mystery of life—it cannot be perceived

because it exceeds the senses, all thoughts and all imagination. It can be known only through mystical insight, which cannot be expressed with words. Tao also is the way of the universe, the driving power in nature, the order behind all life, the spirit which cannot be exhausted. For the masses, the power of the universe was often the power of gods, magic, and sorcery. And Tao refers to the way man should order his life to keep it in line with the natural order of the universe.

The Taoists rejected self-assertiveness, competition, and ambition. They revered humility and selflessness, and were disinterested in the things the world prizes like rank and material goods. Nature was an entity to be made friends with, rather than conquered, dominated, or controlled--the idea being to blend harmoniously with the Tao which flows through everything. Civilization tended to be condemned and simplicity encouraged.

Confucianism. While the Tao is perceived as running through everything, Confucianism focuses on man. And with the exception of Mao, the one name which has become synonymous with China is Confucius. Born only a few years after Lao Tzu (the founder of Taoism) around 551 B.C., the ideas of Confucius permeated every level of Chinese society within a few generations: government offices presupposed a knowledge of the Confucian classics, and spoken proverbs trickled down to the illiterate masses.

Living during a period of great social conflict, Confucius sought to find a way which would allow people to live together peacefully. For Confucius, the answer was derived from selected traditions, handed down from generation to generation; if the continuity were ruptured, then the society broke down. Confucius also further devised what he thought were the values necessary for the collective well-being. These included not only the building of ideal relationships between humans, but also a knowledge of how to behave in a given situation, a set of manners. Behind these concepts is

the presumption that the various roles and relationships of life have been clearly defined.

In the Confucian system of things there are five main relationships: father-son, elder brother-younger brother, husband-wife, elder friend-junior friend, and ruler-subject. What one does affects others, each is never alone when acting; one's actions must not damage or create conflict with other individuals. Confucius reinforced the pre-existing Chinese notion of the family as the basic unit of society. The key to family order is children's respect for and duty towards their parents—filial piety or xiao. Also embedded in this concept is respect for age, which gives everything--people, objects, institutions—their value, dignity, and worth. The old, while at their weakest physically, are at the peak of their wisdom, knowledge, and experience. Respect flows upwards, from young to old.

Lastly, Confucius rejected the use of force and even the notion of a rigid code of law. Conduct could not be enforced by some organization set up for that purpose. Taking legal action also implied an incapacity to work things out by sensible compromise and negotiation advocated by Confucius.

Buddhism. Buddhism is more of a philosophy and code of morality than a religion because it is not centered on a god. Rather, Buddha rejected the supernatural.

Buddha taught that all life is suffering, that everyone is subjected to the trauma of birth, to sickness, to decrepitude, and to death. In Buddhism, the belief is that one is always tied to what one abhors (e.g., an incurable disease or personal weakness), and is separated from what one loves. Real happiness cannot be achieved until suffering is overcome. The cause of happiness is tanha—or desire--specifically, the desires of the body and the desire for personal fulfillment. Happiness can only be achieved if those desires are overcome. This requires following the

"eight-fold path" of the right: knowledge, aspirations, speech, behavior, livelihood, effort, mindfulness and absorption. The right absorption involves the techniques of Hinduism's yoga, a discipline designed to teach control over all the functions of the body. Buddha also accepted the Hindu concept of reincarnation, the cycle of rebirths, and karma, the law of cause and effect.

Contemporary Religion, Culture, and Communism. Besides Taoism, Confucianism, and Buddhism, other religions at one time or another in various places around the country took root and continue to thrive as well. These include Islam, Christianity, even Judaism.

Presently, the Chinese government professes atheism, and considers religion and superstition a tool of ruling classes to keep power and privilege, and an archaic remnant of old China. China's public policies are, of course, strongly influenced by the newer political and economic philosophy of Communism. In brief, Communism professes that the means of production (factories, land) be owned by the people collectively, rather than privately, and espouses policies that benefit society as a whole rather than individuals. Ideally, each individual is to receive according to his/her need. Typically, centrally planned and governed economies are created to transform this philosophy into practice.

Still, freedom of traditional religion is guaranteed under the Chinese constitution, and over the last few years there has been a resurgence in active, organized religion in China. At some places, the monks and priests, driven from temples and monasteries during the Cultural Revolution, have been allowed to return. Other temples have even been renovated and are often attracting many worshippers, in large part, the elderly (Zhong, 1986).

THE CHINESE HEALTH CARE SYSTEM

Health Policies

By all accounts, China has given high priority to public health and medical care since the founding of the People's Republic in 1949. Before 1949, China's population suffered a crippling burden of disease and premature death. Periodic epidemics of plague, cholera, smallpox, etc. swept the land which—combined with frequent famine--sometimes decimated entire populations. These epidemics were superimposed on a high underlying level of morbidity and mortality that continued into 1949. Such occurrences earned pre-Maoist China a reputation as the "sick man of Asia" and led to low levels of life expectancy generally believed to be less than 35 years (World Bank, 1985). Such a state of health reflected a century of political factionalism and social upheaval, much of it caused by foreign traders and foreign armies as China began to open its markets to the world.

For the first three decades of the new socialist regime, Chinese development efforts emphasized two main objectives—development of a heavy industrial base and elimination of the worst aspects of poverty. An important part of the subsequent anti-poverty struggle was to undertake basic public health measures and--relative to other countries—to develop national policies that emphasized public preventive over curative health services for the task of controlling communicable diseases. Experiments in meeting basic health needs were started during the 1930s and 1940s by Mao and the People's Liberation Army while encamped in various provinces. These efforts involved mobilizing the people to educate themselves and encouraging them individually and collectively to provide their own health care and medical care services (Sidel & Sidel, 1974). These experiences generated an

interest in health especially related to rural areas and peasants.[3] Major campaigns were mounted under a strong central policy shortly after 1949 to improve environmental sanitation; to eliminate the "four pests"--rats, flies, mosquitos, and bedbugs; to vaccinate against and cure infectious diseases; and to control the major endemic disorders such as malaria. Mass mobilization played a key role in the success of these campaigns (see, for example, Sidel and Sidel, 1974; and Ma Hai De, 1985). These vigorous prevention efforts, according to a recent World Bank report (1985), were "undoubtedly...enormously successful in reducing morbidity and mortality."

But China's overall emphasis on prevention policy also led to pursuit of a health strategy that reached well beyond the health system per se. In particular, improved nutrition, provision of safe water supplies, sanitary and convenient means of waste disposal, fertility reduction, and widespread educational improvements have been major policy objectives. Again, the recent World Bank's report (1985) concluded that the multi-faceted strategy has been a success, thanks largely to the strong and centralized "administrative capacity and political will of the Chinese government."

The historical emphasis on public preventive measures, however, has not been undertaken while neglecting the importance of curative health measures for the well-being of the population. In fact, the allocation of health resources to preventive activities generated a demand for at least minimal curative services and pharmaceutical availability in even the more remote rural areas. Through 1982, health care facilities for curative services had increased by more than 50 times the 1949 levels. Hospital beds had increased 25-fold, and health professionals had increased by nearly 7-fold,

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3 The farmers and people of the Chinese countryside engaged in agrarian pursuits are popularly referred to as "peasants".

including about 2.7 times the number of physicians as were practicing in 1949 (MOPH, no date).

Public health and preventive measures, combined with curative services, have met with substantial success as evidenced by changes in mortality and morbidity statistics. Average life expectancy has increased dramatically—from about 32 years in 1950 to 69 years in 1982, which is only about six years less than in Western market industralized economies. In addition, success has resulted in the emergence of new leading causes of morbidity and mortality. In urban and much of rural China, parasitic and infectious diseases as causes of death have been substantially replaced by heart disease, cancer, stroke, cerebro-vascular disease, accidents, and chronic respiratory diseases. For example, the mortality rate for cerebro-vascular disease more than doubled between 1959 and 1979 (Wu Ying-K'ai, 1985; Zhou Guanhong, 1985; Li Pei-Yiong and Li Chong-Hui, 1985). Infants, children, and young women have been supplanted by the middle-aged and elderly as the population groups with highest mortality. The older age group also are consuming an increasing proportion of medical care, in large part due to increasing amounts of curative therapies for these increasing problems of chronic diseases (World Bank, 1985).

This shift in disease incidence and prevalence, which has already occurred in industrialized countries, is commonly referred to as the "epidemiologic transition." Urban Chinese disease patterns are increasingly parallel to those in high income countries, and a similar transition is progressing in rural China as well. Still, limited economic capacities have not allowed China to reach parity with the West in health personnel and facilities. For example, in 1982 China had 2.03 hospital beds per 1000 people (as compared with 4.5 per 1000 in the United States). There are 588,000 senior doctors trained in Western medicine and 513,000 senior

doctors trained in "traditional" medicine (discussed in more detail below), yielding a ratio of about 1 senior doctor per 1000 people--about half the U.S. ratio.

The historic shortage of highly-trained doctors plus the national emphasis on prevention has led to a resulting system of greater reliance on the use of indigenous paramedics and other auxiliary personnel to carry out basic educational, preventive, epidemiological tasks, and simple curative work. China, for example, has 445,000 assistant doctors trained in Western medicine who have had two years of medical education beyond junior high school (Statistical Yearbook of China, 1983; AHA, 1982). Most of the primary health care in China is provided by paramedics called "village doctors,"[4] who usually are graduates of primary schools with up to six months of training in public health and primary care. According to Hsaio (1984), there are currently about 1.2 million of these paramedics in China. As the basics of hygiene and community involvement in preventive health become more established, however, it will become necessary to upgrade their skills to undertake more specialized care. The Chinese in fact plan to upgrade 50 to 60 percent of its village doctors to the level of assistant doctor within the decade. Likewise, the increasing prevalence of chronic diseases, which places greater demands on the upper end of the system of health care workers, has led to more intensive training and education for senior doctors—including a greater emphasis on the use of Western technology (Dobson, 1981; World Bank, 1985; Fox, 1984). Sidel (1982) has already noted the decline of village doctors by roughly 22 percent between 1978 and 1982.

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4 In the past, these village doctors have been popularly referred to in the West as "barefoot doctors," though the term is no longer formally used.

There also is fairly widespread evidence (Henderson and Cohen, 1982; Fox, 1984; World Bank, 1985; Hsaio, 1984) that hospital beds, health personnel, and other health resources are unevenly distributed between the urban and rural areas. In 1980, the average number of beds per 1000 people was more than twice the number in urban areas, with the distribution of senior doctors even more uneven: 2.4 per 1000 people in urban areas and 0.5 per 1000 in rural areas.

The Planning Process

Health policy in China is directed by the leaders of the Party and is refined and planned in detail by various levels of an extensive bureaucracy headed by the Ministry of Public Health (MOPH). It extends down to all administrative divisions. Dobson (1981) has noted that in this sense the Chinese planning system is much like that of the U.S., in that a multi-leveled government structure is called upon to resolve and implement national health care policy (e.g., the Medicaid program).

The provincial level bureaucracy is a key planning agent that revises district, county, and municipal applications for resources. Provincial authorities can authorize limited capital construction (such as remodeling a hospital), design health prevention campaigns, transfer and place medical personnel within the province, and act in cases of large-scale medical emergencies. (In such cases, the MOPH may be called upon for extra budget assistance.) Provincial Party committees review the work of the provincial bureaus on policy issues and resource allocation.

Below the provincial level, many health care delivery activities are locally managed at the municipal and district level. Because each jurisdiction has input to the planning and delivery process, goals which at first appear uniform at the national level may be quite varied in

application.

The Ministry of Public Health controls the money for capital construction and purchases of major pieces of equipment and technology. Funds flow from the Ministry through the provinces, to districts, municipalities, and counties. Resource allocation plans are revised as they are passed up through the hierarchical structure. The Chinese planning system, then, might be termed a "top down-bottom up" process. The allocation of funds is determined by need, changes in population, industrial development, etc. Thus, developing areas may receive disproportionately more funding (Dobson, 1981). The MOPH also directly manages a major hospital, vaccine production facilities, the core medical colleges, and medical research institutes (World Bank, 1985).

Overall, though, the MOPH is organized to set general policy only. Power is being increasingly decentralized under the government's new economic policy. This is a marked departure from the 1960s when health policy was centrally formulated under the influence of a limited number of Party members, bypassing the medical establishment and technical planners.

The Organization of Care

For the Chinese, health care is one of the "five guarantees," and despite resource limitations, is organizationally available to all. Chinese health personnel, health stations, and hospitals are organized throughout the nation on a three-tier system of services characterized by increasing complexity and specialization; this system varies in urban versus rural locations.

In rural areas, the first tier comprises barefoot doctors, who provide both preventive and primary-care services. Before 1980, an average of two barefoot doctors (most of whom were also engaged in farming) served 1000

people. For more serious illnesses, barefoot doctors refer patients to the second tier: commune health centers, which may have 10 to 30 beds each, and outpatient clinics, each serving 10,000 to 30,000 people. At the commune health centers, the most qualified medical workers are assistant doctors. Finally, the most seriously ill patients are referred by the commune health centers to the third tier: county hospitals. Each serves 200,000 to 600,000 people and is staffed with senior doctors who graduated from a five-year medical school after completing high school. In rare cases, the patient may be referred to a specialized (tertiary) hospital.

In urban areas, the first tier consists of paramedics working in factories and in neighborhood Red Cross stations, where basic primary care is provided. More serious cases are referred to the district hospitals, and the most serious are referred to municipal hospitals (Hsaio, 1984).

Side by side with the network of national, provincial, and local facilities which serve the entire population, there is a network of industrial and other state enterprise hospitals as well as other facilities that provide free services to workers in those enterprises. In 1981, they provided about 25 percent of medical care in China. Depending on the size of the enterprise, complicated cases are treated in their respective health facilities, or referred to the governmental hospital system. Large enterprises handle almost all their own cases, and the Railway Ministry and Army, to take extreme examples, even have their own medical colleges as well as hospitals (World Bank, 1985).

For post-hospital care, there are few nursing homes at present, but additional homes are being planned. They are administered by district hospitals (Lee, 1985), and each prefecture has at least one, though it may serve other functions as well (Shou Shang Jue, 1985). Home care programs were begun over two decades ago as a solution to the bed

shortage (Meng, 1985), but because home care is provided by hospital personnel, it is available generally only in large cities where it is undertaken by the larger hospitals. It is a program which the Ministry of Public Health favors, though, and currently it is growing at a substantial rate (Wu Yuanjin, 1985).

At first glance, China's patient referral system appears well-organized. Given the relative scarcity of facilities and personnel, criteria for increasingly specialized care should be well-defined to allow improved and more appropriate access to more sophisticated settings. Henderson and Cohen (1982), however, note that a number of factors other than strictly medical ones have produced uneven patterns of which patients receive second and third-level care. For example, geographic and occupational characteristics are strongly related to admission at tertiary care facilities. Most of the patients admitted were urban workers and urban and rural "cadres" (government officials), rather than peasants. In addition, rural patients who ultimately gained admission were generally sicker than urban counterparts. Henderson and Cohen attribute differential patterns of use by urban/rural residents in part to ease of travel and differing levels of perception or sophistication of medical care need. Three times as many urban and government workers were found to deviate from non-standard referral routes in the pursuit of more specialized care. Because access to goods (such as specialized medical care) is often limited, many Chinese are still very much reliant on non-standard approaches, institutionalized privilege systems, and personal connections (guanxi) to supply them with goods and services considered scarce. Lastly, Henderson and Cohen attributed differential patterns of use to stem from very different levels of insurance coverage that exist in China—discussed in more detail below.

Financing Care

Overall, observers agree that policies have reduced financial barriers to health care since the 1949 revolution (Prescott and Jamison, 1984). However, there has never been any public provision for a centralized national health insurance system. At its simplest, health insurance coverage for patients in China can be said to vary by occupation, and (again) there are major differences between urban and rural areas with respect to health care financing.

While preventive and public health programs are almost totally financed by the central government, it pays only 20 to 25 percent of medical services (Cheng, 1982). As previously discussed, government funds go primarily to absorbing capital costs for hospitals and commune health centers, staff salaries in these institutions, and any deficits, including unpaid bills of patients. Operating costs are usually borne by the local cooperative health care financing systems. This means that patients must pay for primary care, the cost of supplies and maintenance of hospitals and health centers, and drugs (which account for upwards of half of health costs) (Hsaio, 1984; Dobson, 1981).

Insurance coverage is designed to cover the patients' costs. In the urban areas where most of the people are employed by the government, military, or state enterprises, health insurance reserves are created and paid for by employers. These workers typically have received complete health care coverage packages and partial coverage for dependents, financed through funds set aside for that express purpose (Prescott & Jamison, 1984; Liu, 1983).

In the rural areas, health insurance has been organized and financed through a cooperative medical insurance system, with money pooled from individual local collective welfare funds and individual monthly premium

contributions.[5] In return, members (peasants) and their families receive "free care," but coverage varies rather dramatically: from 40 percent to 100 percent, depending upon the wealth of the collective--which depends to a great deal on the output of production. Catastrophic care, for example, is frequently not offered by the poorer communes. Health care financing practices, then, are not typically designed to devote large amounts of resources to "save" a very few persons (Dobson, 1981; Hsaio, 1984).

Under the recent economic reforms, self-reliance is emphasized and peasants now receive direct rewards for individual output. This has pushed up production but hurt the collective welfare system as almost 80 percent of the brigades have shifted from collective to household-based production systems. The proportion of the rural population protected by the collective system has dropped from 90 to between 40 and 45 percent (Hsiao, 1984). As a result, many of the formerly salaried village doctors employed by the collectives now minister private fee-for-service practices to a growing group of self-insured patients. For the healthy rural population, the loss of the cooperative insurance reimbursement system has not been a problem. However, those people with serious illnesses have either been heavily burdened by this out-of-pocket system, or correspondingly, facilities and doctors have accumulated large debts.

At the same time, as previously mentioned, the Chinese public-financing

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5 The rural cooperative system was developed in the 1950s after the collectivization and state takeover of the land. Peasants were organized into production teams (100 to 200 people each, corresponding to one or more natural villages), work brigades (averaging 1,000 people each), and communes (averaging 16,000 people each). Under this system, village doctors, like the peasants who worked on the land, received a certain number of workpoints for each working day. At the end of the year, output and profits were pooled at the brigade level, with a portion set aside for a "welfare fund" which financed a large portion of the cost of health insurance (Hsiao, 1984).

system has been further decentralized. Each province or county has become increasingly responsible for the taxing and provision of health and social services, including the payment of bad debts. To what extent the new reforms at the individual and provincial level will further accentuate type and availability of care between prosperous and poor, haves and have nots, remains to be seen.

The Practice of Medicine: Traditional and Western Approaches

There are two distinct streams of medicine in China--"traditional" medicine and "Western" medicine. Until the seventeenth century, the history of medicine in China was synonomous with the history of traditional medicine; external influences and invasions of foreigners were often absorbed and transmitted into the Chinese way of thinking.

Chinese traditional medicine is probably the world's oldest body of medical knowledge, having a history of several thousand years of accumulated empirical observations and abstruse and complex theory. By virtue of its rich and ancient theoretical base, Chinese traditional medicine, which incorporates both diagnosis and therapy, differs from many other systems of folk medicine which are based purely on empirical observations. Diagnosis requires data that are quite different from those gathered by Western doctors, however. Diagnostic methods include observations and questioning of the patient, and detailed and prolonged palpation of the pulse. Diagnosis also may include observation of the patient's temperament, odor, and tongue. Therapy makes use of medicinal herbs, moxibustion, breathing and gymnastic exercises, and acupuncture.

The theoretical concepts of health and disease are based for the most part on a philosophic explanation of nature, on a belief of the unity of man and the universe. It was felt that the human body was constantly influenced

by the complementary forces of yin and yang, and that if all of the forces were in perfect order and harmony, the human body would be in good health. The traditional medicine that has flourished in China, though, has also led to a wealth of empirical observations. Among them is said to be the discovery of the circulation of blood 2000 years before its discovery in the West (Sidel and Sidel, 1983).

With the advent of the socialist regime in 1949, a decision was made to emphasize the traditional medicine approach. This was a policy rooted as much in practicality as in theory, though. China had few practitioners of Western medicine, and consequently, was much more reliant on the use of traditional medicine. The considerable suspicion of Western-trained physicians and intellectuals which existed during the 1950s further damaged the influence and use of Western methods (Dobson, 1981).

While the number of Western medicine physicians is now greater than their traditional medicine counterparts, official Chinese policy in more recent years has been to encourage and develop through education and research not two but three streams of medicine: traditional, Western, and an integrated approach. This integrated approach is intended to borrow the most clinically effective therapies from both traditions to the medical and economic advantage of all (Lee, 1986; Zhong, 1986). Today, Chinese practitioners regularly integrate the two forms of medicine. Traditional physicians, on average, use about 70 percent traditional and about 30 percent Western medicine. Western practitioners reflect similar weights but in the opposite direction. A course of treatment very easily could be initiated in one mode and changed to the other, depending on the circumstances. Similarly, the same patient might receive both traditional and Western medicine for co-existing conditions. In some instances, the treatment itself might represent a combination of traditional and Western

practices (Zhong, 1986; Dobson, 1981).

The decision to apply traditional or Western medicine is made on a case-by-case basis. The physician ultimately decides, but patients do have influence through the intial choice of provider (Wang, 1986). There is some evidence, too, that that the elderly generally prefer traditional approaches (Zhong, 1986; Weddle, 1985). Western medicine, though, is reportedly used in most cases of cancers where surgery is indicated and for coronary conditions (Dobson, 1981).

The use of herbal medicines is integral to traditional medicine. Herbal medicine is frequently in evidence in commune clinics, hospital settings, and in town shops. Varieties of herbal medicines are often stored side by side in racks, to be ground fresh for use orally or to be prepared for injection. In hospital and clinic settings, herbal medicines are also stored in close proximity to Western medicines. Herbal medicines have been reported in Western literature as effective against cancers and blood disorders (Macek, 1984), diabetes, hemaplegia, tumors, (Randel and Ling-Ling, 1983; Jain, 1973) pulmonary disorders (Hyatt and Feldman, 1978), immunological imbalances (Macek, 1984), and management of burn patients (Shi-Tsi-Siang, 1983). There is also evidence that these medicines often produce fewer side effects than comparable Western pharmaceuticals, and are sometimes useful in alleviating side effects of Western drug therapies such as chemotherapy (Macek, 1984).

Acupuncture techniques are perhaps even more integral to Chinese traditional medicine. The traditional medical schools emphasize the use of acupuncture for numerous ailments and for anesthesia; Western schools also train students in its techniques. There is little in Western literature (see, for example, Gaw, et al., 1975) that demonstrates the effectiveness of this technique. However, Chinese practitioners claim a wide range of

treatment possibilities, including treatment of neurological diseases, diseases of the digestive system, infections, acute dysentery, appendicitis, coronary heart disease, intestinal infection, diseases of the respiratory system, asthma, allergies, chronic sinus ailments, diseases of the joints and muscles, mental illness, and shock. Acupuncture is claimed to be particularly useful in pain reduction, reduction of paralysis, and stroke recovery (Sidel and Sidel, 1974; Bischo, 1974; Tan Aiquing, 1979; Dobson, 1981; Meng, 1982). Snow (1971) states that acupuncture treatment is best suited to diseases of the nervous system. Acupuncture anesthesia has also been reported by Dobson (1981) as the preferred approach in 30 percent of surgical procedures.

Utilization Patterns for Services and Procedures

What emerges in this discussion of the Chinese health care system is a picture of tremendous strides in improving the public's health over the last three-and-a-half decades. Its approaches to improving health, and its relating succcesses, have influenced the thinking of health care providers and professionals the world over.

In essence, large-scale and sustained efforts in environmental improvement combined with preventive medical measures (e.g., health campaigns) have greatly reduced the incidence of communicable disease in most of the country. Diffused improvements in basic curative medicine also have greatly reduced mortality rates from the acute illnesses that have recurred (World Bank, 1985).

Such progress largely has been accomplished by utilizing a labor-intensive and low capital-intensive approach to health and medicine. Medical technology and associated styles of practice, until recently, have been notably absent. In the rural areas, sanitation, immunization and

vaccination programs have been dominant. At county hospitals, the level of technological sophistication has been evidenced typically by operating room facilities, as well as x-ray and laboratory facilities (Chen and Tuan, 1983). Only in the urban areas, at the second- and third-level tiers in the medical system, have device and capital-intensive technologies and services been available. At the major municipal and specialty hospitals, as well as the hospitals associated with medical schools, an array of equipment and technology can be found. This is important in that it implies a very different mix of services and procedures for the elderly in China compared to the United States, especially the critically ill. Still, there is very limited evidence and data on available services for the critically and terminally ill.

While reliable statistics on national utilization patterns are unavailable, the existence of intensive care units (ICUs) and coronary care units (CCUs) is fairly well-established in the larger urban hospitals in China. Such facilities typically have EKG bedside monitors, ventilators, blood gas analyzers, and so on (Gao Li, 1985). Many also have sophisticated surgical units and post-surgical recovery units (Chang, 1983). Organ transplantation centers, for example, recently have been established at medical centers in Wuhan (Berki, 1986).

Kidney transplant centers also have been reported in major urban areas. In Beijing, for example, 300 transplants have been performed over the last two years. Donors are often family members (Wu Yuanjin, 1985).[6] Kidney dialysis centers in hospitals and a limited utilization of continuous ambulatory peritoneal dialysis (CAPD) also has been reported (Chiang,

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6 Organ donors are often family members rather than cadavers because Confucian teaching does not allow the dead body to be disturbed. It must be returned to the ancestors.

1983). No data are available on utilization of transplant procedures or dialysis by age, however.

Ventilation and respiratory equipment also are common in larger urban and specialty hospitals (Meng, 1986; Chiang, 1983; Lee, 1986). The availability of MA-1 respirators and defribillators, for example, is made possible for both emergency admissions and the inpatient critically-ill (Chiang, 1983; Meng, 1986; Li, 1986; Lo, 1986; Zhong, 1986; Wang Zan Shun, 1986; Zhou Guanhong, 1986).

Nutritional therapies and antibiotics, on the other hand, are considered basic in China and enjoy widespread use. Taylor and Xu (1986), for example, report that oral rehydration has been used widely in both urban and rural areas for over two decades. Nutritional therapies, too, have been emphasized as basic public health and preventive measures for both the young and the elderly. Greater production of food as well as higher levels of protein-enriched foods have alleviated many of the nutritional deficiencies of the past (World Bank, 1985). Nutritional fads are not uncommon, such as the use of herbal medicines intended to increase strength or to prevent aging. Enteral tube feeding and parenteral nutrition generally are available at second- and third-tier level facilities (He Huide, 1985; Meng, 1985; Heimburger, 1984). One observer has noted, however, that nutrition and nutritional therapies are not being emphasized adequately in China's medical education programs (Heimburger, 1984).

Antibiotics and drug production generally have been extremely important since the beginning of the socialist regime, again in conjunction with China's prevention policies (Wang Zan-Shun and Zhou Guanhong, 1986). Drug production is largely state-controlled and is growing at the present rate of 6 to 7 percent per year. Current production is 14 times greater than in 1957. In recent years there has been a very rapid increase in the

production of drugs for the treatment of tumors and cardiovascular disease. Further, new antibiotics are being introduced in place of the old (World Bank, 1985).

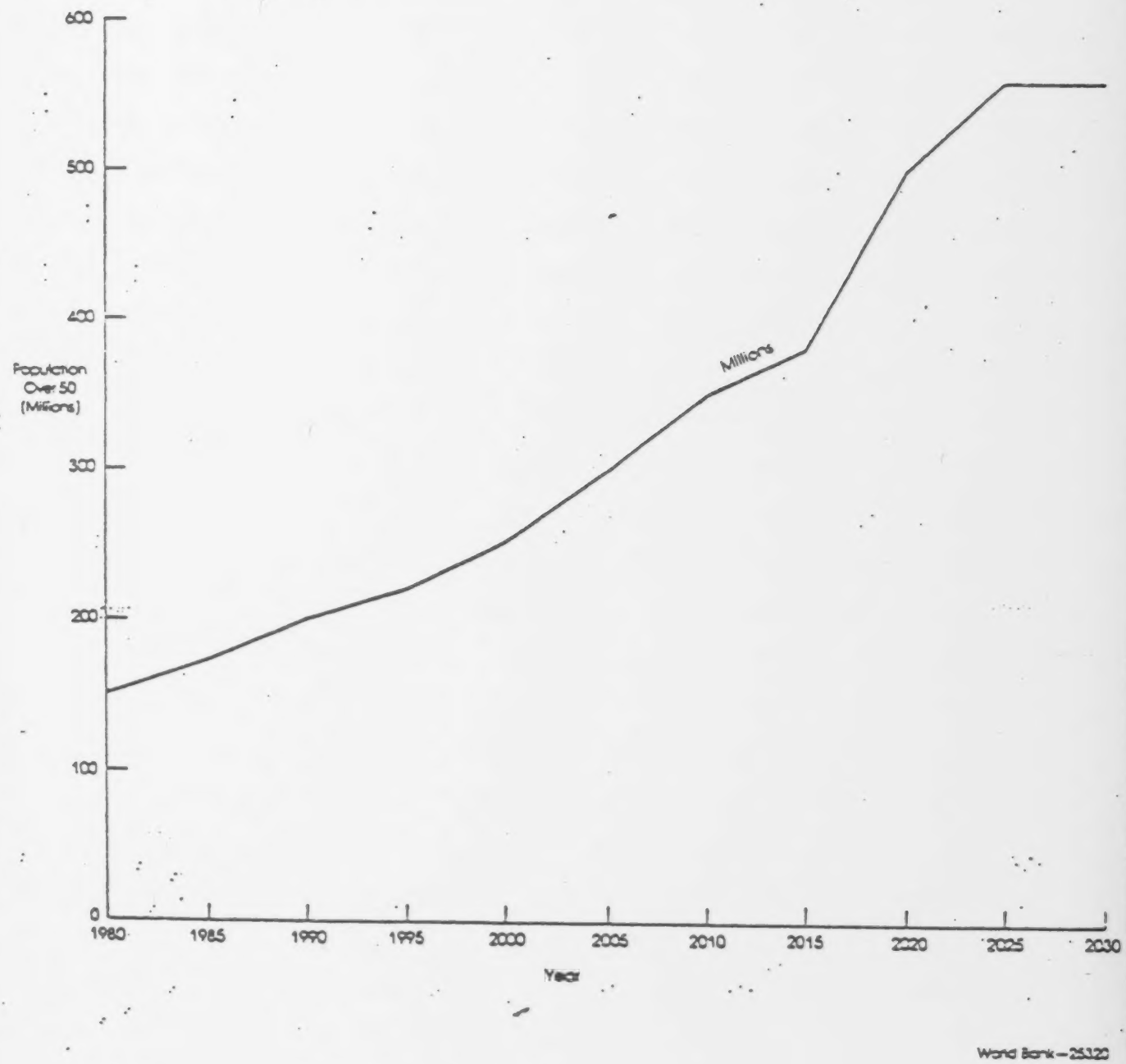
For the future, there are strong indications that China may increasingly move closer to the highly capital-intensive medicine of the West. There already is some evidence of such movement. At least half a dozen CT scanners have been reported available in each of the municipalities of Beijing, Shanghai, and Guangzhou, for example (Teng, 1986; Zhou, 1986; Wang, 1986; Zhong, 1986) Medical schools have emphasized technology utilization in the curricula, and a rapidly increasing number of medical students are receiving training in the West. How prudent such a policy push may be has been questioned, however, because of continued economic constraints and the limited evidence of gains in average life expectancy in the West from the utilization of expensive, technology-specific practice styles of medicine (World Bank, 1985).

THE CHINESE ELDERLY: HEALTH AND WELFARE POLICIES

Social Welfare Provisions

According to the 1953 census in China, there were 64 million men over sixty and women over fifty. By 1985, according to World Bank figures, the number of Chinese over the age of fifty had roughly tripled to just under 200 million (see figure). That number is expected to triple again—to 600 million—over the next 50 years. In terms of percentages, the Chinese National Committee on Aging (Wang Gongshi, 1986) estimates that about 8 percent of the current population is over 60 years old, but by the end of this century the proportion of the nation's elderly will have increased to 13

CHINA:
Projected Population over 50 Years of Age, 1980 — 2030



Source: World Bank (1985)

percent. Such growth in the population of this age group in Western industrialized economies has certainly been the norm, not the exception; but for China it represents a new phenomenon, and policies affecting the elderly are increasingly important and visible.

Since the advent of the socialist regime, China's elderly have typically had two levels of support: the family and insurance (or pension) benefits. For the great majority of the elderly, care and treatment is inextricably bound up with the family. The traditional importance of the family--and the corresponding respect for the elderly members—are legendary. Dominated by Confucian thought, Chinese society has always emphasized the significance of close family and kinship ties. Traditionally, family relationships have provided the individual with not only emotional security and a sense of belonging but also economic, political, and social support. Family became the basis of government, and correspondingly, assumed many of its functions, such as education, dispute settlements, poor relief, and support for the aged (Wu Yaunjin, 1985; Dixon, 1979).

Since the 1949 revolution, the role of the family has been downplayed at various times in an effort to strengthen and prioritize commitments to the state and collective. During the early 1950s, and again during the "Great Leap Forward" of the late 1950s, policies were developed to encourage separation of elderly from their families. Since the 1950s, however, prime responsibility for the welfare of the elderly has remained with the family. Current constitution and marriage laws in fact require that children provide for their parents. Typically, aged parents live with one of their married children, receiving economic support while helping with child care and household tasks (Wu Yaunjin, 1985; Dixon, 1979).

A second level of support for the elderly worker is usually a retirement pension paid out of labor insurance programs; the rural peasant also is

provided a guarantee to the basic necessities of life and a funeral. For both pensioners and the rural peasant, continued medical care coverage is provided, as part of an overall benefit package. Elderly workers, though, are generally encouraged not to retire and seek income support, but rather to continue gainful employment for as long as possible. Still, once the minimum pensionable age is reached, usually 60 for men and 55 for women, monthly financial assistance can be received until death. The individual pension rate is usually pegged to length of service and wage rate immediately prior to retirement. The elderly peasant in the rural areas, on the other hand, never seem to fully retire. Rather, responsibilities diminish with age and capabilities, but never completely cease until death is near. The lack of financial independence relative to the urban worker generally creates dependence upon family for the peasant (Wang Gongshi, 1986; Ma Hai De, 1985; Dixon, 1979).

For the aged without families, limited accommodations are available. Rural communes have set up so-called "homes of respect" for the elderly. Likewise, municipalities and provincial governments have built a limited number of facilities and centers for the elderly and disabled with no families. Somewhat worrisome is the impending demand for accommodation for the elderly with no families. This demand is expected given China's one-child family policy.[7] The policy appears to be meeting with some

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7 In 1979, Sichuan province instituted a policy designed to persuade married couples to have no more than one child. This policy was backed by a system of incentives to parents who agreed to have no more than one child, and penalties for those who persisted in having more than two. Because of great leaps in the population and decreases in infant mortality rates over the last three decades, this policy was soon embraced as a national policy, and all provinces have now adopted such incentive and disincentive systems—including a provision that living standards will be maintained when they become old or widowed (World Bank, 1985).

success, especially in the urban areas such as Shanghai. To this point, though, there has been no systematic planning for social support policies and programs necessary for the elderly and widowed parental population (Ma Hai De, 1985; World Bank, 1985; Wang Gongshi, 1986; Yu, 1986; Dou, 1986; Shou Shang Jue, 1986).

The elderly are usually encouraged, even obliged, to involve themselves in neighborhood or community activities, especially social services. They also are encouraged to educate themselves or to learn new handicrafts. Cultural groups, activity centers, and 61 so-called "universities of the elderly" have been organized and provided, especially in the larger urban areas. Several of these organizations teach basic preventive and self-care skills and behaviors, such as T'ai Chi exercises and principles of good nutrition (Zhong, 1986; Wu Yaunjin, 1985).

The Emergence of Geriatric Medicine

Previous discussions have touched on the health care system in China and the various aspects of care that affect the elderly. There is no evidence to indicate that patterns of care for the elderly differ substantially from other age groups. As pointed out at several junctures, levels of insurance coverage, urban-rural location, and specific placement in the three-tiered system of services are the more significant determinants of care for all age groups in China. Unlike the special financing programs in the U.S. (e.g., Medicare and Medicaid) established for the elderly, health care insurance for the elderly is no different from insurance for their younger counterparts. Health care schemes do vary, though, according to service in government, military, factories, or rural countryside.

The changing disease patterns of greater prevalence of illness of the aged (such as chronic illness) and the rapid increase in the numbers of

elderly, though, have refocused medical education, research, and care to some degree within the last five to ten years. For example, while no reliable figures are available, a substantial number of general and teaching-affiliated hospitals (above the district level) have opened special units as well as outpatient clinics for so called "geriatric diseases", including hypertension, coronary heart, chronic bronchitis, and so on. A number of hospitals also have been reported to initiate policies giving priority to the elderly for outpatient services. Newly established rehabilitation medicine centers and pharmacies also have established priority service for the elderly and commonly-found geriatric afflictions such as arthritis, stroke, and hip fracture (Zhou Guanhong, 1986; Wu Yuanjin, 1985; Meng, 1986; He Jang Go, 1985; Lee, 1986; Li, 1986, Wang Gongshi, 1986; Lo, 1986).

Research and evaluation in connection with geriatrics also has sprouted in medical schools, colleges, and hospitals at all levels. The first geriatric research and treatment center is under construction in Beijing. Research across the country includes longitudinal studies of individuals who reach advanced age, diseases commonly afflicting the elderly, mortality and morbidity studies, investigations on the mechanisms of the aging process, predictive modelling of geriatric incidence and prevalence rates, and the immunology and psychology of the aged. In addition, a number of efforts have been initiated to investigate preventive approaches to care for the elderly, and the use of traditional medicine approaches in diagnosis and treatment. Several professional organizations and journals focusing on the elderly recently have been created. For example, the China Gerontological Association (which studies clinical care, but plans to expand its scope to include social and economic conditions), and the Chinese Society of Geriatrics (which establishes standards of practice and gathers data related

to treatment) have both been established only within the last five years (Zhou Guanhong, 1986; Meng, 1986; Lee, 1986; Li, 1986; Lo, 1986; Wu Yuanjin, 1986; He Jang Go, 1985; Wang Gongshi, 1985).

Treatment of the Critically- and Terminally-Ill Elderly

Bioethical Framework. Not surprisingly, the changing demographics and disease patterns, as well as the initial glimmer of high technology medicine, have forced the Chinese to begin facing more frequent questions concerning life, death and appropriate treatment for its elderly. Until recently, a relatively well-defined bioethical framework and the relative paucity of technologic opportunity have clarified treatment decisions. While the Confucian ethic imbues the Chinese with a tradition of love, respect and support for the aged, this has never necessarily translated into treatment at all costs for survival's sake (Dixon, 1979). Reinforcing this attitude is the more recent socialist ethic that chooses public health measures and prefers minimum levels of medical care for the masses over advanced treatment for the few.

At the risk of oversimplifying, the ethical imperative in the American health care system might be characterized by the welfare of the individual, whereas in China, the "welfare of the group" is the guiding principle. Furthermore, the Chinese Taoist/Confucius tradition of congruity, harmony, and the common good has minimized conflict and surrounding ethical dilemmas over interpretation of this principal. As Fox (1984) has observed, there is a noticeable lack of conscious discussion or concern over ethical dilemmas in China relative to concerns in the United States. (As Fox also implied, though, the individualism, competition, pluralism, and wealth of this culture have had the reverse effect of in some sense "breeding" ethical dilemmas surrounding treatment decisions.)

Decisionmaking Surrounding Treatment. Discussions with physicians and providers in China typically reveal that treatment decisions surrounding the critically-ill elderly begin with proper diagnosis. Once that is determined, a judgment is made whether available treatments will be "life-saving" or "life-prolonging" (Meng, 1986; Wing, 1985). This distinction is critical because providers will unhesitatingly begin to administer treatment in the case of the former. Importantly, "life-saving" for the Chinese implies not only basic physiological functioning, but the return to some level of normal, productive living for the individual. For example, if an individual is diagnosed as suffering a brain hematoma, and despite its removal, the patient may linger indefinitely in a coma, the operation will frequently not be done. Such decisions do not seem to be age-specific; at least one case of dialysis being denied a small girl because of permanent brain damage has been reported in the literature (Fox, 1984).

According to Meng (1986), the Chinese are particularly discerning in cases of needed surgery because of (or at least the perception of) post-operative complications or long recovery periods. On the other hand, if a patient has been diagnosed with some chronic or terminal illness, but treatment can even temporarily restore the individual to a normal, productive regimen there is typically little hesitancy (Lee, 1986). For example, the administration of traditional herbs and medicines for cancer patients as a palliative (rather than restorative approach) is not uncommon. Similarly, the Chinese have some hospice-like facilities, either freestanding or more typically as distinct-part units of larger hospitals, for the terminally ill. Such care is also provided in small hospitals, particularly those associated with factories and universities, where beds may be available (Meng, 1985). Drug therapies, often traditional medicine

approaches, are administered to maintain the patient in a comfortable state until death (Yu, 1986; Dou, 1986).

The strong exception to treat/not treat decisions for live-saving situations is the medical emergency. A fairly clear consensus among Chinese providers is to apply all necessary procedures—resuscitation, ventilation, and so on—to save and stabilize the patient until a decision about further treatment plans can be decided upon (Li, 1986). In the larger hospitals, teams of specially-trained emergency room personnel are often available for resuscitation procedures. Only with patients in advanced stages of cancer do physicians readily forego resuscitation measures (Shou Shang Jue, 1985).

Once the patient is placed on mechanical ventilation or other life-sustaining technologies, withdrawal of treatment becomes more difficult. Brain death is not used as a criterion for withdrawal either, but must be accompanied by the stopping of the heart (Meng, 1985).

Despite policy efforts in the recent past to downplay the importance of the nuclear family in China, it is the family that usually decides upon appropriate treatments. The individual patient may or may not be told of the diagnosis and corresponding clinical choices, but rarely does the individual decide alone. Instead, it is the appropriate family members—the parents in the case of a younger person, the son or daughter and spouses in the case of the aged. It is also the family that is informed <u>first</u> of the clinical status of the patient, and death is never explicitly discussed with the patient. There is no evidence that written consent forms are ever used in connection with treatment. Likewise, there would appear to be no formal procedure mechanisms for attaining consent, though tradition and custom have regularized the process to a significant extent (Meng, 1986; Fox, 1984; Lee, 1986; Wang, 1986; Gao Li, 1985).

On the other side of the consultation process, it is interesting to note

that doctors in China are not necessarily advocates of treatment like their Western counterparts. Further, there is little evidence that Chinese governmental or legal authorities attempt to impose explicit ethical choices (outside of broadly established boundaries) as is sometimes the policy in the United States, such as with the recent case of Baby Jane Doe (Fox, 1984). In the event that treatment is refused, the patient is normally sent home. Many who refuse, though, may seek treatment elsewhere, receive the same advice, and later consent (Meng, 1985)--perhaps to assure continued hospital care. More problematic are patients who, on their own or through their family, insist on treatment against the physician's recommendation. A physician may agree to provide treatment in order to avoid complaints to the hospital administration or to the local health bureau (Lee, 1985; Geng, 1985).

Closely related to this issue is the issue of malpractice. Medical malpractice as Americans know it would not appear to be an issue in China. Confucian tradition precluded the historical growth of a body of common law, and there is no civil law to settle disputes among individuals. Not surprisingly, liability insurance is largely unneeded as a result. What is needed, however, is the assurance that the proper diagnostic and therapeutic regimens are being undertaken. To assure this, physicians often work in teams, and develop consensus when difficult cases are deliberated over. Chinese physicians do fear not only the possibility of clinical mistakes, but the possible public embarrassment and "loss of face". Even so, physicians rarely are penalized in any form by the state, and peer review processes are both rare and non-binding--education (or "re-education") is usually the only "punishment" (Tung, 1986; Lee, 1986; Fox, 1984). According to Geng De-Zheng (1985), patients or families can request hospitals to compensate for provider mistakes. Institutional committees, not courts,

though, evaluate the individual case and make the decision concerning the level of just compensation. Large, urban hospitals may have one or two such cases per year. The largest single payment awarded to date has been 4,000 yuan—about $1,200.

Lastly, according to Lee (1986), the Chinese are now struggling in the public forum with the issue of the right to forego treatment. Currently, before the People's Assembly in Beijing is a proposal whereby physicians would not be obligated to treat the patient if the following patient conditions are present:

- the patient is in the final state of a disease,
- the heart has stopped beating for 5 minutes or more, or
- respiration has not taken place for 20 minutes or more.

The proposal, however, is given little chance of enactment in the near future.

Economic Factors. Economic and financing factors increasingly affect treatment decisions in the new China, especially since the institution of its market reforms. As previously discussed, levels of insurance coverage together with placement in the urban or rural transfer/referral system are crucial determinants of the type of care received, as well as the availability and patterns of utilization of Western technologies (Henderson and Cohen, 1981). Additionally, these factors will in large part determine eligibility for placement in special geriatric research and treatment centers discussed earlier (Meng, 1986). Other than placement in these units, though, available evidence points to undifferentiated utilization patterns of procedures and technologies for the critically-ill elderly/non-elderly within individual hospitals or facilities. If, for example, a large specialty hospital in Shanghai was well-equipped with ventilator-assisting drugs, dialysis machines, and specialty units, differences in use reflected levels of coverage and case mix rather than

patients' ages (Zhou, 1985; Wang Gongshi, 1986).

This was rather overtly argued by at least one Chinese administrator of a newly formed and non-government supported hospital in the south of the country, who stated that even if a patient was near death but had no insurance, s/he would be transferred or sent home as quickly as possible. The insured patient, on the other hand, would be given treatment (regardless of effectiveness) as long as it would be requested by the family (Lo, 1986). Similarly, it is not uncommon for the rural, poorly-insured patient to have much shorter hospital stays on average than his urban, well-insured counterpart. Indeed, there is some evidence that families in urban areas often will request that their relative be kept in the hospital as long as possible--even until death. In the new China, more and more urban patients are dying in the hospital, not at home. This in part reflects the housing shortages in urban areas in present-day China, and reflects the inability of families to care for the elderly at home given that husband and wife are commonly both employed full-time (Lee, 1986). Meng (1986) has observed that keeping relatives in the hospital also assures against legal/social allegations of neglect.

On the provider side, the vast majority of physicians are salaried at levels predetermined by the government (Hsiao, 1984). Unlike the situation in the United States, there is little resulting economic incentive to undertake unnecessary surgery or procedures. Likewise, they are often constrained by the limited availability of medical equipment and supplies. A reverse situation is the government subsidizing of pharmaceuticals, vaccines, and antibiotics. To the extent that the price of these is set artificially low, opportunities and some evidence (World Bank, 1985) exist as to their overutilization.

Through all of this discussion surrounding decisions to treat the

critically- and terminally-ill elderly, it is important to again keep in mind that China is changing. In the pursuit of modernization and national wealth, individualism, competition, and pluralism are assuming new significance. As a few selected medical centers Westernize and modernize, and physicians move away from salary-based payment, differing styles and levels of quality of care may generate a whole new set of decisionmaking processes and ethical dilemmas. One clue may be the recent experience in relatively affluent, modern, and largely Chinese (98%) Hong Kong, where rationing policies for kidney dialysis have recently been developed, and which largely place the elderly last after most other groups in priority of available care (Lam, 1986).

IMPLICATIONS FOR AMERICAN POLICIES

Chinese providers and policymakers largely believe that China has much to learn from the western experience in the treatment and care of the critically-ill elderly. This has been observed in China's recent demonstrations that it may want to become the latest eager American imitator in its pursuit of technologies such as CT scanners and specialism. Nevertheless, there would seem to be important lessons that the Chinese can offer this country.

For one, Chinese traditional medicine and a wide variety of other herbal and medical preparations have possibly provided the Chinese with cost-effective alternatives to more expensive Western therapies. Unfortunately, little is known or understood empirically about levels of safety, efficacy, and effectiveness of traditional approaches and regimens. Important efforts now are underway in China to improve biochemical knowledge of the active ingredients in many of the herbal preparations, and attempts

to initiate scientific inquiries into this area enjoy strong support from the Ministry of Public Health. Some American drug companies and universities (e.g., the University of Kentucky) have performed research in this area (Henderson, 1986). Because the manufacture of Chinese drugs, pharmaceuticals, and other preparations are exclusively under the control of the government, though, there is little market incentive (in terms of new markets in China) for American concerns to invest in this area. Due to the potential application in American medicine, though, Congress may want to consider incentives to firms in this country to carry out research and development efforts. Such incentives could include grants or cooperative agreements, or financial tax incentives similar to those structured under the recent Orphan Drug legislation.

Secondly, the policy direction in China to decentralize clinical and economic decisionmaking to the extent possible warrants careful watching. Early evidence indicates that this policy will generate greater disparities of access and quality care than presently exist. The United States also has experienced such lessons in the past that parallel this experience. For example, the Kerr-Mills legislation in the early 1960s authorized health care coverage for the indigent elderly, but delegated much of the financing and decisionmaking to the States. One result was unacceptable differences in the provision of benefits and resulting care. The recent impetus to privatize and further decentralize health programs for the elderly not only should reflect upon historical American experience, but upon contemporary Chinese lessons as well.

Thirdly, despite the current infatuation with expensive medical technology and the relative disregard for their true cost-effectiveness, the Chinese have made efforts and inroads in designing and implementing prevention policies and strategies for its elderly and chronically-ill.

Because of the success with preventive policies for acute illnesses, the social, political, educational, and economic planning and programs in this area may provide the U.S. and other Western nations lessons and opportunities for more health care cost savings. This is especially important as long as the primary concern in the U.S. system continues to be cost-containment.

There obviously are important differences between China and the United States. These include differences in the stage of development and industrialization, demographic profile, nature of historical health problems, degree of cultural uniformity, differences in interplay between scientific and folk beliefs about health and illness, and differences in political and economic systems. These differences should not obscure our increasing similarities, though, or the lessons that are possible for both nations.

REFERENCES

American Hospital Association, Hospital Statistics, Chicago, IL, 1982.

Berki, Sylvester, University of Michigan School of Public Health, Ann Arbor, Michigan, personal communication, January 1986.

Bischo, J.J. "Observed Uses of Acupuncture," China Medicine As We Saw It, John E. Fogarty International Center, U.S. Department of Health, Education, and Welfare, Publication No. (NIH) 75-684, Washington, DC, 1974.

Capra, Fritjof, The Tao of Physics, Bantam Books, New York, NY 1976.

Chang, M.K., "Nursing in China: Three Perspectives," American Journal of Nursing, Vol. 83, No. 3, pp. 389-91, March 1983.

Chao, L.M., Gong, Y.L., and Gu, S.J., "Financing the Cooperative Medical System," American Journal of Public Health, Vol. 72 (Supplement), pp. 78-80, 1982.

Chen, Pi-Chou, and Chi-Hsien Tuan, "Primary Health Care in Rural China," Social Science and Medicine, Vol. 17, No. 19, pp. 1411-17, 1983.

Cheng, X.M., and Ye, X.F., "Cost Analyses of Medical Care," American Journal of Public Health, Vol. 72 (Supplement), pp. 81-82, 1982.

Dobson, Allen, "Health Care in China After Mao," Health Care Financing Review, Winter 1981, Washington, DC, 1981.

Dou, Ze-Min, Ministry of Public Health, Beijing, People's Republic of China, personal communication, January 1986.

Fisher, G. Sandra, The Organization of Social and Supportive Services for Older People in the United States: Implications for Social Servies in China, U.S. Administration on Aging, Washington, DC, 1985.

Fox, Steven, "Hippocrates Unbound: China's Medical Education for the 1980s," JAMA, Vol. 251, No. 4, pp. 490-94, January 27, 1984.

Fox, Steven, "China: Diary of a Barefoot Bioethicist," Hastings Center Report, pp. 18-20, December 1984.

Gaw, A.C., Chang, L.W., and Shaw, L.-C., "Efficacy of Acupuncture on Osteoarthritic Pain," New England Journal of Medicine, Vol. 293, No. 8, pp. 375-78, 1973

Geng, De-Zheng, Beijing, People's Republic of China, personal communication, December 1985.

Guangdong Provincial Institute of Geriatric Medicine," A Comprehensive Study on Centenarians in China," unpublished, People's Republic of China, no date.

Guangzhou, Yi-Shou Hospital, "A Brief Introduction," unpublished, Guangzhou, People's Republic of China, no date.

He, Huide, Beijing, People's Republic of China, personal communication, December 1985.

He, Jang Go, Beijing Hospital, People's Republic of China, personal communication, December 1985.

Heimburger, Douglas, "Observations on the Practice of Clinical Nutrition in Hospitals in China," Journal of Parenteral and Enteral Nutrition, Vol. 8, No. 6, pp. 628-31, November/December 1984.

Henderson, Alfred, Embassy of the Uited States of America, Beijing, People's republic of China, personal communication, January 1986.

Henderson, G., and Cohen, M.S., "Health Care in the People's Republic of China: A View from Inside the System," American Journal of Public Health, Vol. 72, No. 11, pp. 1238-1244, November 1982.

Hsaio, W.C., "Transformation of Health Care in China," New England Journal of Medicine, Vol. 310, No. 14, pp. 932-936, April 5, 1984.

Hyatt, R., and Feldman, Robert, Chinese Herbal Medicine: Ancient Art and Modern Medicine, Schocken Books, New York, NY, 1978.

Jain, K.K., The Amazing Story of Health Care in New China, Rodale Press, Emmaus, PA, 1973.

Lao Tzu, The Way and Its Power, no date.

Lee, Zhi-Sia, Chinese Medical Association, Beijing, People's Republic of China, personal communication, December 1985 and January 1986.

Li, C.P., Chinese Herbal Medicine, U.S. Department of Health, Education, and Welfare, Public Health Service, National Institutes of Health, Publication No. (NIH) 75-732, Washington, DC, 1974.

Li, Gao, Beijing, People's Republic of China, personal communication, December 1985.

Li, Pei-Xiong, Guangdong Provincial Institute of Geriatric Medicine, Guangdong Province, People's Republic of China, personal communication, January 1986.

Li, Pei-Xiong, Haung, P., Li, C.H., and Ju, L.K., "Hypertension in the Elderly in China," Guangdong Provincial Institute of Geriatric Medicine, unpublished, Guangdong Province, People's Republic of China, no date.

Liu, Y.C., "China: Health Care in Transition," Nursing Outlook, Vol.31, No. 2, pp. 94-99, March/April 1983.

Liu, Yuen Chow, "China: Traditional Healing and Contemporary Medicine," International Nursing Review, Vol. 31, No. 4, pp. 110-114, 1984.

Lo, Timothy K.C., Gangzhou Yishou Hospital, Guangzhou, People's Republic of China, personal communication, January 1986.

Ma, Hai De, "History of Eradication of Venereal Diseases in the People's Republic of China," presentation at the National Institutes of Health, Bethesda, Maryland, August 13, 1985.

Macek, Catherine, "East Meets West to Balance Immunologic Yin and Yang," JAMA, Vol. 251, No. 4, pp.433-439, January 27, 1984.

Meng, Jia-Mei, Beijing Second Medical College, People's Republic of China, personal communication, December 1985 and January 1986.

People's Publishing, Statistical Yearbook of China, Beijing, People's Republic of China, 1983.

Prescott, N. and Jamison, D.T., "Health Care Sector Finance in China," World Health Statistics Quarterly, Volume 37, No. 4, pp. 387-402, 1984.

Randel, S., and Soong, Ling-Ling, "Traditional Chinese Medicine in China," The Western Journal of Medicine, Vol. 39, No. 2, pp. 236-238, August 1983.

Samagalski, Alan, and Buckley, Michael, China: A Travel Survival Kit, Lonely Planet Publications, Berkeley, CA, 1984.

Shi-Tzi, Siang, "Use of Combined Traditional Chinese and Western Medicine in the Management of Burns," Panminerva Medica, Vol. 25, 1983.

Sidel, V.W., "Medical Care in China: Equity Versus Modernization," American Journal of Public Health, Vol. 72, pp. 1224-26, 1982.

Shu, Shang Jue, Beijing, People's Republic of China, personal communication, December 1985.

Sidel, Victor W., and Sidel, Ruth, A Healthy State: An International Perspective on the Crisis in United States Medical Care, Pantheon Books, New York, NY 1983.

Sidel, Victor W., and Sidel, Ruth, Serve the People: Observations on Medicine in the People's Republic of China, Beacon Press, Boston, MA, 1974.

Snow, Edgar, Red China Today, Vintage Books, New York, NY, 1971.

Steiner, R.P., "Acupuncture: Cultural Perspectives (2. The Eastern View)," Postgraduate Medicine, Vol. 74, No. 4, pp. 71-78, October 1983.

Summerfield, John, Fodors People's Republic of China, Beijing, 1979.

Tang, Vincente, Embassy of the United States of America, Beijing, People's Republic of China, personal communication, January 1986.

U.S. Department of Health, Education, and Welfare, Medicine in Chinese Cultures: Comparative Studies in Health Care in Chinese and Other Societies, Kleinman, A., Kunstadter, P., Alexander, E.R., and Gale, J.L. (editors), Government Printing Office, Washington, DC, 1975.

Wang, Gongshi, China National Committee on Aging, Beijing, People's Republic of China, personal communication, January 1986.

Wang, Jiu Le, Ministry of Public Health, Beijing, People's Republic of China, personal communication, January 1986.

Wang, Zan-Shun, Hua-Dong Hospital, Shanghai, People's Republic of China, personal communication, January 1986.

World Bank Atlas, Population, Per Capita Product and Growth Rates, World Bank, Washington, DC, 1983.

World Bank, China: The Health Sector, Washington, DC, 1985.

Wu, Yaunjin, Secretary General, National Committee on Aging, Beijing, People's Republic of China, personal communication, December 1985.

Wu, Ying-Kai, "Epidemiology and Community Control of Hypertension, Stroke, and Coronary Heart Disease in China," unpublished, Chinese Academy of Medical Sciences, Beijing, People's Republic of China, no date.

Yu, Wen-fan, Ministry of Public Health, Beijing, People's Republic of China, personal communication, January 1986.

Zhang, Lin, Beijing, People's Republic of China, personal communication, December 1985.

Zhong, Zhichang, Health Bureau of Guangdong Province, Guangzhou, People's Republic of China, personal communication, January 1986.

Zhou, Guanhong, "A Report on the Prevention and Treatment of Geriatric Diseases in Shanghai," unpublished, Shanghai Public Health Bureau, People's Republic of China, no date.

Zhou, Guanhong, Shanghai Public Health Bureau, People's Republic of China, personal communication, January 1986.